

**THE ROLE OF CULTURE AND HEALTH BELIEFS IN TYPE 2
DIABETES SELF-MANAGEMENT BEHAVIOURS AMONG THE
BLACK SUB-SAHARAN AFRICAN COMMUNITIES IN THE UK**

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**A thesis submitted in partial fulfilment of the requirements of Nottingham Trent
University for the degree of Doctor of Philosophy**

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Dedication

I would like to dedicate this thesis to my late father, Mr Andy Oyewole, I wish you were here to witness my success, but I know you are very proud of your daughter even in heaven. I love you, dad.

Acknowledgement

I would like to sincerely appreciate everyone that has contributed tirelessly and given their utmost support towards the completion of my PhD.

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Glory to God for the journey so far!!!

Abstract

The prevalence of type 2 diabetes as a multifaceted public health issue has become a growing health problem, particularly among people from the Black sub-Saharan African (BsSA) communities. BsSAs self-management behaviours and choices of treatment are embedded in their cultural background and lay belief systems, often creating disengagement with the formal health care and services. When such a situation arises, they seek treatment from both conventional and unconventional care systems, reflecting the sociocultural context of diabetes management.

The research draws upon a qualitative approach to identify the significance of culture and lay belief systems on self-management behaviours among the Black African community. This study presents the narratives from semi-structured interviews with twenty-eight Black sub-Saharan African living with type 2 diabetes, ten healthcare providers and six stakeholders. Analysis of data was informed by the sociocultural model and PEN-3 public health cultural model, which moves beyond individualistic and bio-medical explanations of diabetes.

The findings from the study revealed that experiences, perceptions and treatment goals vary among the BsSA communities. BsSAs seek treatment approaches that they trust and found to be livable, manageable and efficient. Thus, they develop systems of self-management and healing, suitable for their beliefs, values and personal priorities. Cultural beliefs and medical pluralism were found to be of paramount importance in self-management of diabetes among the BsSA communities. Culturally appropriate services from health care providers and the knowledge of healing through a holistic approach to health were seen as critical for diabetes intervention and informing ways of optimising health care services among BsSA communities.

The study contributes to the existing knowledge on the significant role and underlying principles of cultural values and beliefs on T2D self-management behaviours among BsSA communities. Diabetes self-management behaviours among the BsSA communities are influenced by shared beliefs, collective sense of being in an identified cultural identity and community togetherness. In addition, this study complements the use of a cultural framework and qualitative research in the interpretation of self-management and health-seeking behaviours that are culturally grounded in beliefs, norms and morals. A broader interpretation of individuals' narratives of diabetes, their social and cultural context, and their relationships with health care providers contribute to the debate on the interpretation of health between a lay belief system and medical professional knowledge within the mainstream health system. Developing engagement strategies grounded in lay belief systems lived experiences and cultural identity could facilitate the development of collaborative and culturally appropriate interventions that could promote positive self-management behaviours among people from the Black African communities.

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List of terms and abbreviations

APPGD – All-Party Parliament Group for Diabetes

BALWD – Black Africans living with diabetes

BME – Black and Minority Ethnic group

BMI –Body Mass Index

BsSA – Black sub-Saharan Africa

CAM – Complementary and Alternative Medicine

CCG – Clinical Commissioning Group

CHI – Commission for Health Improvement

CSDH – Commission on Social Determinants of Health

CVD – Cardiovascular disease

DAFNE – Dose Adjustment for Normal Eating

DAWN – Diabetes Attitude, Wishes and Needs

DCM – Decision Maker

DEAL – Diabetes Education and Awareness for Life

DESMOND – Diabetes Education, and Self-Management for Ongoing and Newly Diagnosed

DKT – Diabetes knowledge test

DH – Department of Health

EPP – Expert Patient Programme

EVT – Expectant Value Theory

GP – General Practice

HBM – Health Belief Model

HCP – Healthcare professionals/Healthcare providers

HPM – Health Promotion Model

HQIP – Healthcare Quality Improvement Partnership

HWB – Health and wellbeing board

IDF – International Diabetes Federation

IPQ-R – Illness Perception Questionnaire

JHWS – Joint Health and Wellbeing Strategy

JSNA – Joint Strategic Needs Assessments

NAO – National Audit Office

NCAPOP – National Clinical Audit and Patient Outcomes Programme

NDA – National Diabetes Audit

NDIA – National Diabetes Inpatient Audit

NDPP – NHS Diabetes Prevention Programme

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

HSCIC - Health and Social Care Information Centre

NSF-D – National Service Framework for Diabetes

PHE – Public Health England

PHOF – Public Health Outcomes Framework

PLM – Policymakers

PLWD – People living with diabetes

QOF – Quality and Outcome Framework

SABRE – Southall and Brent Revisited

SCT – Social Cognitive Theory

SDGs – Social Development Goals

SDH – Social Determinants of Health

SDSCA – Summary of diabetes self-care activities

SM –Self-Management

TPB – Theory of Planned Behaviour

TRA – Theory of Reasoned Action

T2D – Type 2 Diabetes

UK – United Kingdom

WHO – World Health Organisation

CHAPTER 1

INTRODUCTION AND OVERVIEW OF RESEARCH

An introduction to the research context, prevalence, incidences and implication of diabetes in the United Kingdom is presented first, before laying out the research problem, gaps in the literature to be researched and the implication of the study. Additionally, this chapter introduces the research problem, rationale, aim, and objectives of the study. The chapter also identified the original contributions proposed by this study. The final section of this chapter is a presentation of the structure of the thesis and the summary of the chapter.

1.1 Research context

Diabetes is classified as one of the fastest growing diseases in the United Kingdom (UK), especially among people from the Black African origin (Tillin et al., 2012; Diabetes UK, 2016a). Diabetes self-management awareness and health outcomes continue to make headlines due to the potential risk of social, environmental, political and cultural factors being recognised as major determinants (Kendall et al., 2011; Abubakari et al., 2013; Harrison, 2014). This study explores the interrelationship and influences of cultural values and health beliefs associated with type 2 diabetes (T2D) self-management behaviours, examining the views and experiences of Black sub-Saharan Africans (BsSA) living with T2D, health service providers (HCPs) and policymakers (PLMs) from across the city of Nottingham, its local statutory partners and the local voluntary and community sector. Research on the impact of cultural differences and effects on diabetes care among Black Minority ethnic (BME) groups in the UK have been conducted; however, there are limited studies and a significant knowledge gap in how cultural factors shape both diabetes policies and self-management practices among BsSA communities in the UK. In-depth understanding

of people's cultural beliefs, and how these influence health decisions and diabetes-related health outcomes are essential for prevention and control strategies in diabetes self-management programmes.

This study aims to shed light on the way BsSAs living with T2D conceptualise their health behaviours through culture and how BsSAs, healthcare providers (HCPs) and policymakers perceive the implementation of lay belief system and a social-cultural framework into diabetes self-management programmes. A qualitative research method informed by ethnography was chosen for the study to understand the lived experiences and perspectives about self-management among the BsSA communities. This methodology allows for an in-depth understanding and non-medicalised description of their health behaviours.

1.2 Background

1.2.1. Classification of diabetes

According to Deshpande et al. (2008) study, diabetes mellitus is described as a chronic metabolic disorder of the endocrine system, broadly characterised by insulin sensitivity and impaired glucose control that can alter metabolism in the body. People living with diabetes (PLWD) are often unable to process sugar from their diet, resulting in an increased level of blood glucose; sometimes termed hyperglycaemia (Deshpande et al., 2008; WHO, 2017). There are different types of diabetes mellitus; these are type 1, type 2 and gestational diabetes (Diabetes UK, 2016b). The symptoms of the different types of diabetes are similar: excessive urination, excessive thirst, weight loss, fatigue and vision difficulties, although they are likely to be less marked in those with T2D (WHO, 2015). Although there are different biochemical

agents and medicines available to control the irregularity in the insulin level of people with diabetes, total recovery from diabetes is yet to be reported in studies.

1.2.2 Global prevalence of diabetes

The incidence and prevalence of diabetes, especially T2D, are increasing globally but the levels vary in different countries, and has become a severe threat and concern to public health and populations (Whiting et al., 2011; WHO, 2016). Diabetes is a global health problem identified to be increasing disproportionately, affecting approximately 8.3% of the population and responsible for 8% of all global mortality between the ages of 20-79 years (WHO, 2011; Diabetes UK, 2016b). According to WHO (2011), the mortality rate of diabetes will increase by 50% in the next ten years due to the reduced life expectancy of 6 years for anyone diagnosed in their 50s. This report demonstrates the relevance of diabetes as one of the fastest and growing health problems in the world. The statistics reflect the significant impact that diabetes has on people's health, quality of liveliness and life expectancy of the population affected and the health maintenance system (Diabetes UK, 2014a; Diabetes UK, 2014b).

Diabetes, therefore, is not only a serious health problem for individuals affected, but also has a significant impact on the health and economic system. The statistics reported by Diabetes UK (Diabetes UK, 2016b) showed that the increased prevalence of diabetes over the years in the UK had presented a multi-faceted challenge to the health systems, health care costs and expenditures in the UK. Also, diabetes poses as one of the leading causes of death both in the UK and in other countries around the world (Diabetes UK, 2016a).

1.2.3. Diabetes-related complications

Diabetes places a substantial burden on health status, economic status, and quality of life of individuals (Diabetes UK, 2016b). It can have significant impacts on the physical, psychological and material well-being of individuals and their families (Diabetes UK, 2016b). Diabetes can result in other severe comorbidities and a high risk of complications. The effect of diabetes mellitus is a long-term condition that is usually incurable, leads to severe damage to the body system over time and can be life-threatening if not properly managed (Deshpande et al., 2008). Complications from T2D are long term. These complications include microvascular complications such as neuropathy, retinopathy, renal failure, and peripheral vascular disease (Molitch et al., 2015; WHO, 2015); macrovascular or cardiovascular complications such as heart disease and stroke, (Zaninotto et al. 2007) and other poor health-related conditions (Diabetes UK, 2016b). The list of complications reflects the potential severity of diabetes if uncontrolled. Complications from diabetes if not treated and properly managed can lead to an increased risk of severe health complications including, sight loss, renal failure, nerve damage leading to lower limb amputation, and premature death. This can also increase the risk of mortality resulting from coronary heart disease, kidney disease, kidney failure, heart attack, stroke and depression (Oldroyd et al., 2005; McCormack and Grant, 2013; Diabetes UK, 2016b). All these complications are extremely costly to manage, compared to the cost of monitoring and treating diabetes as a health condition (Kanavos et al., 2012). However, early diagnosis, adequate diabetes care and self-management can reduce long-term cost and prevent risk or impacts of complications (Tillin et al., 2013; Diabetes UK, 2014b). Even though diabetes is a serious health condition, prevention and targeting high-risk populations to help prevent and manage the disease can help halt the incidence (Molitch et al., 2015).

T2D is a long-term condition with serious adverse outcomes, and its complications are disproportionately high among ethnic minority groups compared to the general population in the UK (Diabetes UK, 2016b). This disproportionality has been related to different social, geographical, economic, environment structural risk factors. For example, culture, ethnicity, genetic predisposition, fat distribution, sedentary lifestyle, physical inactivity, obesity and lower socioeconomic status (Oldroyd et al., 2005; Wilson et al., 2012; Patel et al., 2015). T2D can be initially treated by adhering to recommended diet and active exercise for weight loss, however, the management of T2D poses a challenging process of a long-term health condition and complications with limited scientific knowledge on the cure for the health problem. Nevertheless, evidence from previous studies has shown the onset of T2D can be delayed, or even prevented with effective management of the health condition which can increase life expectancy and reduce the risk of complications (Diabetes UK, 2014a; WHO, 2015, Diabetes UK, 2016a).

1.3 Burden and implication of diabetes in the UK

In the UK, T2D as a long-term health condition and its related complications have been identified as a growing public health concern and has presented significant challenges to the health system in the UK (DH, 2012). The prevalence of T2D over the years in the UK has become a significant burden for the economy and the health care system, in terms of increasing incidence, escalating costs associated with treatment and complications. Although the exact cost to the National Health Service (NHS) is unclear, the cost estimation on health care support, services and management recorded £10 billion spent on diabetes, which was about 10% of the total NHS budget in 2012 and this cost is estimated to increase to £15billion by 2035 (Hex et al., 2012; Diabetes 2016b). People with diabetes are more likely to be hospitalised in comparison to people without diabetes because of the increased cases of

complications (Hex et al., 2012). There is an estimated figure of one out of ten people admitted to hospital with cases of diabetes, which sometimes increase to one out of five depending on the age group (Diabetes UK, 2010). Complications of diabetes make up to one in five cases of all CVD (Cardiovascular disease), foot and renal admissions in the UK (NDST, 2005; Diabetes UK, 2014a). The financial burden of diabetes is not limited to the NHS. It is currently estimated that a total cost of £9.8 billion direct cost and £13.9 billion indirect cost, is spent on diabetes treatments and its complications in the UK. This is a combined yearly cost of £23.7 billion, and it is predicted to rise to £39.8 billion in 2035-36 (Hex et al., 2012; Diabetes, 2014a; Diabetes UK, 2014a). England spending on inpatient care alone for diabetes is around £2.3-£2.5 billion per year, about 10% of the total NHS inpatient care expenditure (Kerr, 2011). T2D is a health condition requiring a high-level of independent healthcare and management with more concerns about the costs of diet, lifestyle and behavioural change, physical activities and medication, personal impact on people with diabetes and their families, and complications (Diabetes UK, 2014a; Diabetes UK, 2016b).

The proportion of direct spending on diabetes treatments and complications

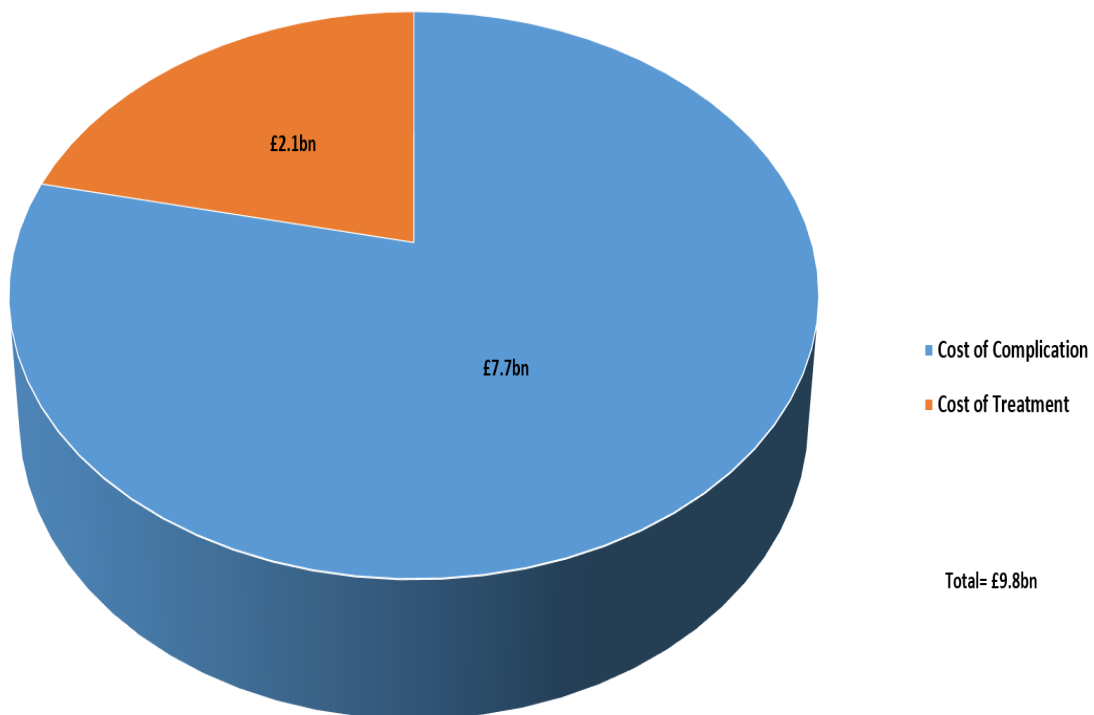


Figure 1.1. The proportion of direct spending on diabetes treatments and complications

(Source: Hex et al., 2012)

The number of people in the UK diagnosed with diabetes has risen from 1.4 million in 1996 to nearly 4.5 million in 2016 (Diabetes UK, 2015) compared to previous estimates that this will grow to 5 million by 2025 (Diabetes UK, 2012a). This increase could, however, be attributed to better diagnosis, monitoring and awareness (Diabetes UK, 2016a). Despite the UK healthcare system and management, diabetes continues to be an important concern for public health due to the significant increase in mortality and morbidity rates, and health inequalities, which are caused by the prevalence of the diseases in the society (Egede et al., 2002). According to Egede et al. (2002) and Diabetes UK (2010), most of the cases in the increased mortality and morbidity rate in diabetes incidences are the results of an ageing population and rapidly growing numbers of people that are overweight and obese. Likewise,

the assessment report by The NHS Health Check Programme showed that the patterns of the prevalence are alarming, and it is four times higher than the incidence of all cases of cancer combined and is yet going up, making it the most significant health challenges confronting the UK health system (Diabetes UK, 2012b). It was estimated that about 850,000 people with T2D remain undiagnosed and this may present with advanced health complications like retinopathy, neuropathy or arterial disease (Holman et al., 2011; Diabetes UK, 2012a). Furthermore, 50 percent of people with T2D would have shown signs of the risk of complications at diagnosis (Diabetes UK, 2009a). People living with T2D are more likely to have other major cardiovascular diseases (CVD), for example, heart disease and stroke which is the primary cause of diabetes mortalities shortening the life expectancy of people with diabetes by 5-10 years compared to nondiabetics (Kanavos et al. 2012). Each year, T2D is associated with 75,000 deaths in the UK, which amounts to 24,000 excess deaths compared to what would have been expected for this health condition (Diabetes UK, 2012c). People with T2D in the UK experience an average reduced life expectancy of about 6years when diagnosed under 60 years of age (IDF, 2015).

As previously stated that T2D is a costly health condition with a high risk of severe health complications, it also time-consuming to treat and manage (Kanavos et al., 2012; Diabetes UK, 2016b). One out of 20 people with diabetes incurs social services, cost or care cost because of complications (Diabetes UK, 2016b). Reducing the burden of diabetes requires lifestyle and behavioural intervention for prevention, early diagnosis to ease management and high quality of treatment and healthcare to delay or prevent early detection and treatment of complications that could result from the disease.

Diabetes affects some population groups more than others, so also does obesity, which is a major risk factor for developing diabetes. Approximately, a third of the increase in type diabetes prevalence is attributed to obesity, with a focus on individual lifestyle, while the rest of the figure is due to age and the changing ethnic structure and disparities of the UK population (Holman et al., 2011; Diabetes, 2013b). Due to the impact of obesity on T2D, the rise in the prevalence of diabetes continues to increase disproportionately among different ethnic groups, as part of the rising prevalence of obesity in the society (Diabetes UK, 2016b). Findings from the Southall and Brent Revisited (SABRE) study reveals the full extent of the risk of developing T2D among Black Minority ethnic population in the UK (Tillin et al., 2013). This study was conducted for a period of 20 years among South Asian, African and African-Caribbean. This study revealed that by age 80, approximately half of South Asian, African and African-Caribbean would have developed diabetes compared to European descent. Although several influences have emerged as contributing factors, family history, health education, self-management and social support were identified to be significant risk factors among the Minority Ethnic population. Similarly, the National Diabetes Inpatient Audit (NDIA) report shows that the majority of the people diagnosed with diabetes between the age of 35 to 80 years is men compared to diagnosis rate for women (HSCIC, 2013). These gender differences were observed to be because of differences in the regular health care visit, prioritisation and attitude to health, independently facilitated self-management and acceptability of diabetes among the gender group (Gale and Gillespie, 2001; HSCIC, 2013).

1.4. Research problem

With increased sedentary lifestyle and progression of complications, diabetes has become the most significant disease burden in the UK in terms of increased medical costs, mortality and morbidity. In the UK, people of Black African origin are up to three times more likely than

people of White European origin to be diagnosed with T2D (Diabetes UK, 2016b), are more at risk of developing diabetes-related complication at a younger age, and these are mostly characterised in the literature by an unhealthy lifestyle and diet (Tillin et al. 2012; Hinder and Greenhalgh, 2012; Diabetes UK, 2016b). Adherence to treatment and health-promoting lifestyle, which includes medical and insulin therapy, diet regulation, physical activity, blood glucose monitoring and lifestyle modification, are the set guidelines for T2D prevention and self-management to reduce the risk of mortality and morbidity (Diabetes UK, 2009a; NICE, 2012b). While these measures are fundamental to achieve optimum control and management of diabetes and reducing the risk of complications, only a few people living with T2D engage in the recommended levels of diabetes self-management and intervention programmes (APPGD, 2015). Moreover, the Black sub-Saharan African (BsSA) population is one of the ethnic minority groups with known health disparities, especially in health problems related to unhealthy behaviour and lifestyle, such as obesity, diabetes, cardiovascular disease and other health complications resulting from the individuals' ways of living and management (Harrison, 2014; Diabetes UK, 2016a). However, this group has been under-represented in recent studies on diabetes management.

Black sub-Sahara African (BsSA) communities

In this study, the term BsSA identifies people whose geographical origins are from the sub-Saharan region of Africa (Figure 1.2 below). It is a term widely used to differentiate them from white Africans living south of the Sahara region and those from the northern region of Africans, which are of the Arab descent. It also gives the communities' specific identity within the wider black communities that may also include African Caribbean.



Figure 1.2. The brown colour shows the area referred to as Sub-Sahara Africa.

(Source: Google maps, 2016)

Understanding the beliefs about T2D and other contributing factors are important to comprehend how people make sense of their illness and their attitudes to management (Harvey and Lawson, 2009; Patel et al., 2015). Over the last decade, there has been a shift from an emphasis on the individual being responsible for their health towards recognising the influence of a social, economic and collective model of health (Eckersley, 2006; Unger and Schwartz, 2012). Several studies have reported that the prevalence of T2D among ethnic minority groups can be attributed to range of complex and interrelated factors such as socioeconomic factors, environmental factors, cultural factors, and other external factors,

such as, Government policies (Agyemang et al., 2009; Noakes, 2010; Johnson et al., 2011; Abubakari et al., 2013). Although many of these studies have reported these factors in relation to adherence to care services, treatment effectiveness and patient-provider communication (Higginbottom, 2006; Brown et al., 2007), there is a significant gap in the research literature related to the influence of sociocultural factors on diabetes self-management behaviour among BsSA communities in the UK. Although previous studies found that beliefs about medicine, perception about diabetes and other behaviours instigating illness management contributes to poor adherence and poorer health outcomes, much of this research has been conducted with the African Caribbean and British South Asians (Brown et al., 2007; Johnson et al., 2011; Patel et al., 2015). To date, qualitative research conducted among the BME groups has not captured how cultural beliefs shape and influences diabetes self-management behaviours among the Black African (BA) populations and their lived experience. It is, therefore, significant to examine the engagement of BsSAs in diabetes self-management practices and the role of cultural beliefs on self-management behaviours because it can contribute to the literature related to diabetes self-management behaviours and social determinants of health.

Hinder, and Greenhalgh (2012) argue that the increased prevalence of diabetes has not been adequately reduced by behavioural changes or social factors associated with diets, exercise and lifestyle. This is because the focus on the role of individual lifestyle tends to overlook other sociocultural factors that constitute individual behaviours and shape health beliefs (Unger and Schwartz, 2012; Nettleton, 2013). Moreover, T2D management is associated with sociocultural practices such as cultural beliefs, sedentary lifestyle and use of alternative remedies (Chowdhury et al., 2000; Kohinor et al., 2011; Harrison, 2014) with a high tendency of non-compliance with treatment and management regimens. Nevertheless, several

studies argue that diabetes treatment and prevention largely depends on an individual's willingness to self-manage their illness, regardless of cultural or social factors (Brown et al., 2007; Helman, 2007). Other studies have also argued the demand for further cultural sensitive programmes to identify cultural factors as essential factors in diabetes self-management and diabetes intervention (Noakes, 2010; Johnson et al., 2011; Abubakari et al., 2013; Patel et al., 2015). Thus, the need to explore culturally harmonising and health-promoting disease self-management strategies are imperative for the high-risk population.

Several influential sociocultural factors have been identified to contribute to the embracing of health-related behaviours, engagement in health care intervention programmes and health disparities among individuals with T2D (Uskul, 2010). Global health system and health policies in the UK remain structurally positioned within a biomedical model of disease, creating tensions for the control of public health agendas between the medical model, and community lay-perspectives and belief systems (Nettleton, 2013; Clark, 2014). Epidemiology and scientific-based methods, despite the social determinants of health (SDH) agenda, remains the main discipline of public health (WHO, 2011). There has been less focus on people's culture and health beliefs, and health interventions which are implemented tend to be based on epidemiological studies and professional top-down solutions reflecting the perspectives of health practitioners (Nettleton, 2013) and not on people's experiences and narratives. On the other hand, many studies conducted and reviewed showed that T2D treatment varies largely among ethnic groups in the UK (Brown et al., 2007; Hinder and Greenhalgh, 2012; McCormack and Grant, 2013). Although several studies assessed the effectiveness of intensive treatment and educational programmes for diabetes in the UK, unsatisfactory and poorer outcome of diabetes care and management among ethnic minority group, have also been reported in different health literature and health care system in the UK

(DH, 2012; Nottingham Insight, 2016). Some of these programmes include NHS Health Check, Structured Education Programme for T2D, Diabetic Retinopathy screening, Cardiovascular Disease Prevention Programme (DH, 2008c).

Existing commissioned diabetes services focused on obesity, weight management and glucose monitoring, but there is growing recognition of the local authorities that these services could be more efficient for people from BsSA communities if they utilised a culturally sensitive approach to care (Sharma et al., 2014). The culturally sensitive approach the various cultural norms, social expectations and belief system that could help facilitate efficient access to those individuals that are not currently engaging with the support available (Sharma et al., 2014). According to Oldroyd et al. (2005), cultural explanations and ethnic difference explanations of self-management among the African population becomes observable and evident when health beliefs and behaviours associated with the ethnic group concerned is established and recognised as a significant factor. Hence, the need for a further investigation to verify individual factors that could be used to provide an insight to the importance of cultural and health beliefs and how these play a significant role in self-management behaviour, adherence to health care and intervention programmes.

1.5. Purpose of the study

The purpose of this research was to propose a model that could be used to investigate the role culture and health belief may play in improving diabetes self-management behaviours and health outcomes among BsSA communities in England. Furthermore, the research seeks to elucidate the impact of existing diabetes policies in the UK, mainly because the existing strategies and intervention for diabetes remain structurally positioned within the medical

model. Moreover, this study aims to assess the cultural factors that influence and enables self-management behaviours to identify the most appropriate and culturally sensitive programmes that could enhance positive health behaviours and improve health outcomes among the BsSA population. Consequently, policymakers and HCPs (GPs, nurses and community healthcare providers) could direct their efforts to the most influential cultural factors present among this population.

1.6. Significance and contribution of the research

1.6.1. Importance of study

In the UK, T2D among people from Black African origin poses a significant public health challenge. Although its prevalence varies widely among different ethnic populations, the rate of incidence has increased over the years (Diabetes UK, 2016a). When diabetes is not adequately managed and controlled, the increased morbidity and mortality rates lead to an increase in health inequalities and greater financial burdens on the NHS (Diabetes UK, 2016b). Besides, enhancing the quality of life for people with long-term conditions such as T2D is one of the strategic priorities set out in the NHS outcome framework for 2016-17 (Coulter et al., 2013). This includes an emphasis on commissioning of services at a community level, particularly among BsSA communities where there are higher numbers of people with long-term conditions and poorer health outcomes. Also, improving the wider determinants of health is one of the Public Health Outcome framework indicators for 2016-19 (PHE, 2017c). This includes an emphasis on the improvements in broader factors that affect health and wellbeing and health inequalities. Thus, assisting and educating people with diabetes to change their unhealthy behaviour and providing policymakers with sufficient information to guide in the development of required policy will help in the improvement of

health and economic outcomes, benefitting both the service providers and service users, families, communities and society.

Many studies have explored and examined the importance of diabetes self-management among ethnic minority groups, in terms of improving clinical and health outcomes, reducing health risk factors, reducing unhealthy behaviours, complication, and cost of diabetes care. Nevertheless, research conducted among ethnic minority population in the UK is not sufficient to identify and elucidate the in-depth understanding of the impact of culture and health on self-management behaviours among the BsSA communities and how these influential factors can play a significant role in improving health outcomes, adherence to treatment regimens and quality of life for people with T2D in the BsSA communities. The social, economic and collective model of health has increasingly influenced behavioural change approaches to health promotion (see comprehensive discussion in 2.7). However, culture as a modifying factor is yet to be implemented within the integrative approach when working with the BsSA communities. The multi-faceted nature of T2D, therefore, requires integrated, cohesive and holistic approaches shaped by a sociocultural perspective for promoting self-management practices among people with T2D to reduce the increasing burden of diabetes long-term complications improve health care delivery and reduce health inequalities.

The purpose of this research is to explore peoples' beliefs and cultural understanding of diabetes management through their experiences, which is often disregarded when producing culturally specific treatment plans and information. Additionally, the use of qualitative research informed by the ethnographic approach of inquiry to understand the various practices and behaviours influencing individual's health decision can contribute to the

promotion of a holistic and effective cultural-sensitive intervention for people living with T2D. The sociocultural approach identifies that cultural beliefs and practices about health and healing play an important role in an individual's decision-making and experiences of health and illness (Hahn and Inhorn, 2009). The result from this study will inform a culturally sensitive framework as guidelines that will encourage HCPs and policymakers to adopt and develop diabetes self-management policies and guidelines needed to account for cultural health beliefs and practices in consultation to identify barriers to diabetes management. Understanding the sociocultural factors that influence people's behaviour and health decision can assist to modify health behaviours suitable for an ethnic group.

At baseline, the research will explore the cultural beliefs among BsSA communities and how their shared experiences influence diabetes management behaviours and health-seeking decision. It will explore the experience of diabetes treatment and management among African communities in the UK since the effective intervention, and successful self-management of T2D requires not just attention on behavioural change, physical activities and diet but the underlying attitudes and beliefs which drive that behaviours and lifestyle.

1.6.2. Contribution to existing knowledge

The original contribution to knowledge proposed by this research offers an empirically based account of self-management practices among BsSA communities to Public Health programmes and primary care providers. Also, the study will contribute rich qualitative data to understand better the dynamics of holistic, culturally oriented approach and community engagement in health intervention programmes. This knowledge will provide a clearer insight into the cultural factors that augment diabetes self-management and lay understanding of health that challenge the biomedical view supported by conventional medicine. Besides, this

study seeks to contribute to the health belief theory and sociocultural model of health behaviour by identifying cultural and health belief factors relevant to diabetes self-management and health care. This study offers socially constructed knowledge that will inform health intervention developers, educators and HCPs about cultural beliefs and experiences with T2D self-management and the cultural barriers influencing noncompliance and lack of adherence of people living with T2D to adequate health care interventions and advice. Furthermore, the theories used in this study will allow other researchers to use the sociocultural approach for further research on diabetes self-management and health-promoting behaviours, and adaptation approach for different population groups with other life-threatening diseases.

Finally, the ultimate issue underlying this study is reducing the health inequalities and improving quality of life. It is expected that this study will identify ways through which understanding and accepting people's cultural values and beliefs can contribute to the meaning of health, approach to behavioural change, and improved well-being.

1.7. Aims, Objectives, and Research Questions

1.7.1. Aims of research

The research aims to explore and provide an analysis of the role of cultural factors and health beliefs in T2D self-management among Black Africans in a large city in the UK. It also explores current health policies and guidelines for diabetes healthcare, assesses its conventionalism with the ongoing challenges of the prevalence of diabetes in the UK and the prominent role in the new public health.

1.7.2. Objectives of research

- To review the literature on the management of type 2 diabetes.
- To identify the common barriers and challenges related to diabetes self-management intervention among BsSA community.
- To draw on the comparison of people's interest and experience with diabetes self-management of their culture and belief system to ascertain the impact on health outcomes.
- To critically analyse the implication of sociocultural approach in self-management for diabetes policy and practice in the UK.
- To identify and propose a culturally sensitive strategy for diabetes management that will serve as an effective measure to reduce health inequalities and for improved health outcomes among the BsSA communities.

1.7.3. Research questions

The following are the research questions guiding the study.

1. How do cultural values and beliefs influence self-management behaviours among BsSA communities?
2. How does diabetes self-management practices vary among the Black African communities?
3. What value do BsSAs with T2D place on the use of alternative and/or traditional medicine for diabetes self-management?
4. How do HCPs engage with cultural beliefs of BsSAs in the management of T2D?
5. How do people with T2D, service providers and policymakers perceive culturally sensitive intervention for self-management and implications for policy and practice?

1.8. Justification and scope of research project /Overview of research methodology

1.8.1. Rationale for research project

This study considers the broader social and cultural factors that underpin the rising prevalence of T2D among the BsSA community. As such, this study draws upon the fields of social science, public health and sociology. This study will assess T2D management beyond the conventional medical orientated and individualistic approach of behavioural change. It will consider sociocultural perspective, which allows the construction of knowledge that could enrich public health perspectives on addressing health inequalities and the broader determinants of health behaviours. This research will be exploring both the formal and informal structures of public health, such as the elite institutions involved with developing health policy at a national level, and the wider informal networks, e.g. community groups, through which the majority diabetes care management operate. The informal networks will be providing a channel to explore emerging new paradigm epistemologies, such as cultural model and lay knowledge, challenging the conventional scientific paradigms of positivism of the health sector among Black African populations in the UK. Therefore, this will help to recognise the shift in the balance of power to a community and lay-knowledge orientated approach and allowing the engagement of a holistic reflection of people's life experiences to improve public health intervention programmes for people living with diabetes (PLWD).

1.8.2. Scope of research

This research will focus on a specific geographic location in Nottingham, which is in the East Midlands region of the United Kingdom. The area has been chosen for two main reasons; first is geographic convenience and existing contacts with the BsSA communities in the city, secondly is the considerable increase in the incidences of T2D among BsSA communities in

Nottingham. There are currently a comparatively large number of people in Nottingham City with undiagnosed T2D. The prevalence estimates of diagnosed diabetes in 2015/16 was 5.5% in Nottingham City compared to 6.5% in England (See figure 1.3). Based on the NHS Nottingham City CCG report, 54% of people with T2D are from the most deprived quintile compared to 24% in England (PHE, 2017b). Also, the further risk of mortality for people with diabetes was 32.8% in NHS Nottingham City CCG, for England the additional risk was 39.2% (PHE, 2017b). The comparison of mortality figure in Nottingham compared to England is presented in Figure 1.4 below

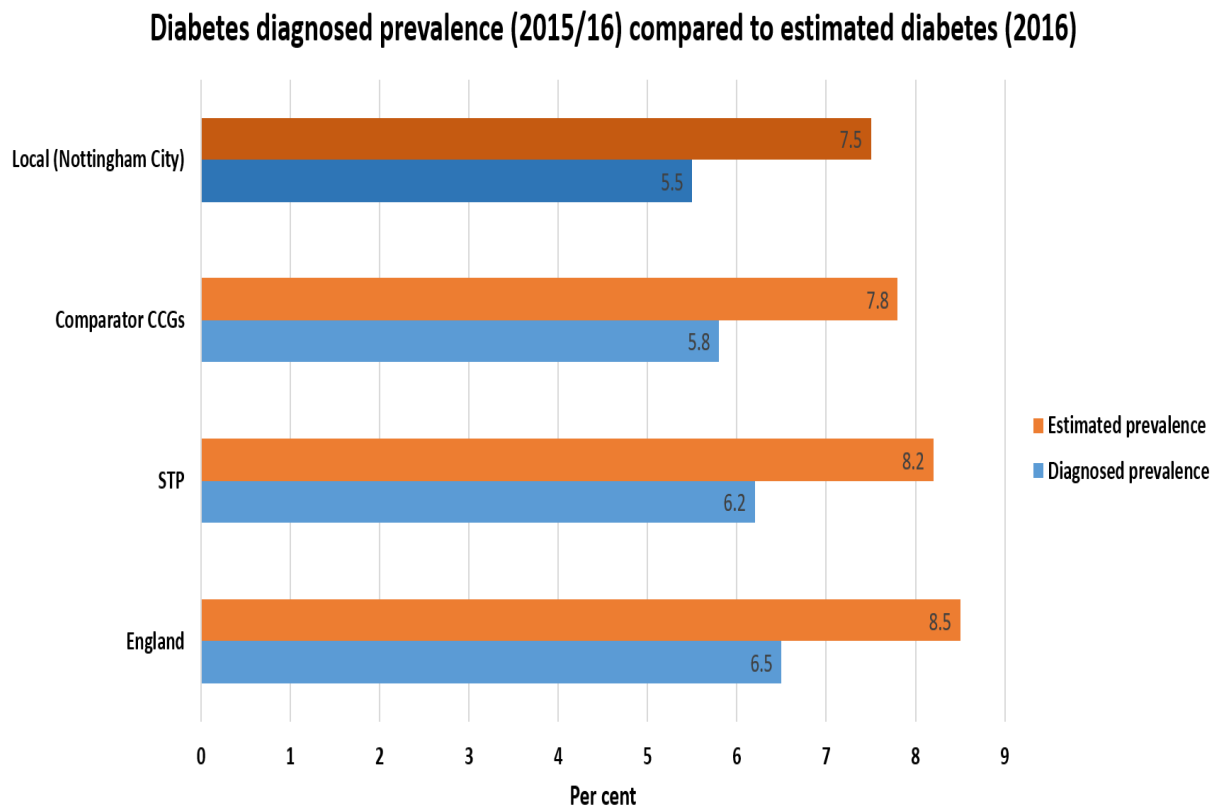


Figure 1.3. Diabetes diagnosed prevalence in Nottingham compared to England

(Source: PHE: Cardiovascular Disease Profile, Diabetes, 2017b)

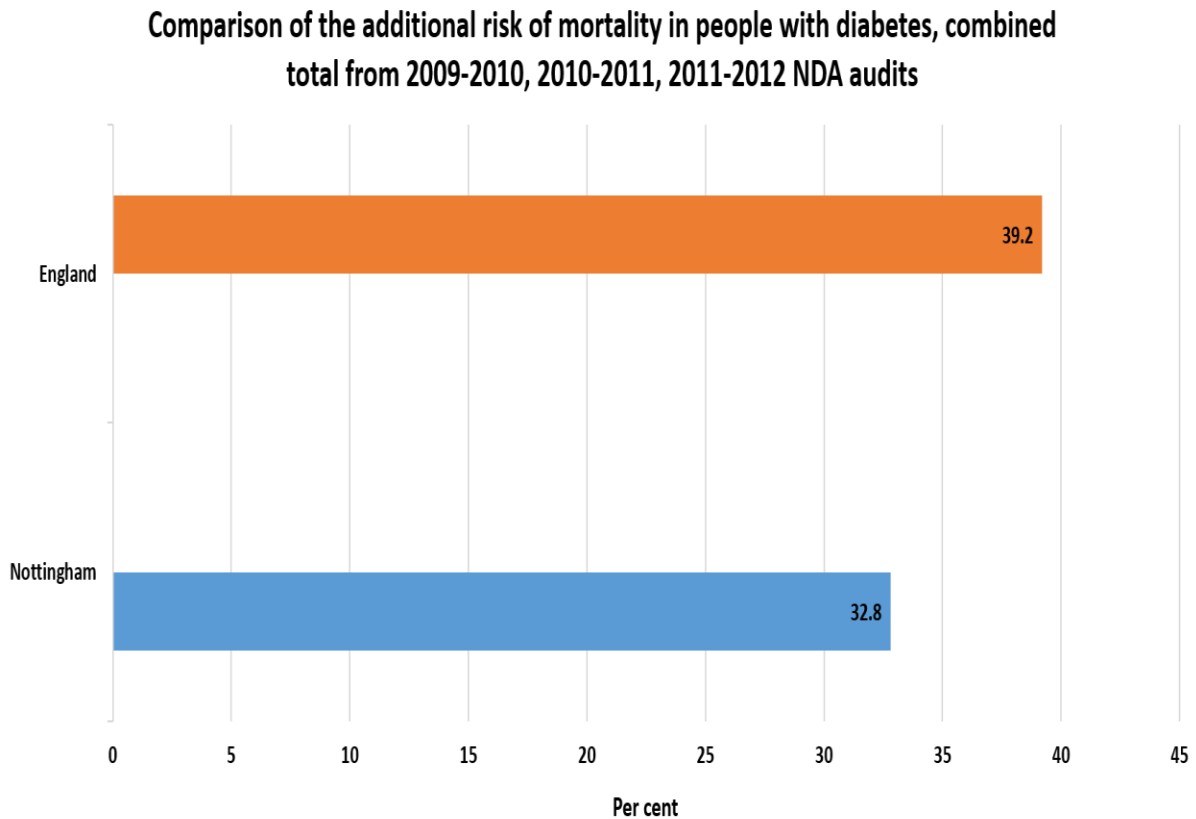


Figure 1.4. Comparison of mortality figure in Nottingham compared to England

(Source: National Diabetes Audit (NDA) 2015/16)

Local health and support groups have been known to provide advice and support for people from the Black African communities. As such, they can offer feedback to the policymakers' report on their findings and recommendations to health providers. Some of such prominent local support group, especially in Nottingham is the Nottingham Community and Voluntary Service (NCVS), and Black, Asian and Minority Ethnic (BAME) health outreach who have been working locally to assist people from the Black and minority ethnic (BME) communities (Nottingham Insight, 2016).

1.9. Structure of Thesis

This section outlines the structure of the thesis. The thesis comprises of seven chapters, and each of the chapters has subsections to give a clearer understanding of the research study.

Chapter 1- presents the background and overview of the research study, its research context, aims and objectives, research questions, the scope of research and structure of the thesis

Chapter 2 – Diabetes prevalence and management among BsSA communities: provides the overview of the available literature and existing evidence related to the key research context, concepts and issues covered in the study. The chapter focuses on the background information on diabetes as a national public health issue, particularly among Black African populations in the UK. Also, it discusses the evidence about the burden and implications of diabetes prevalence among Black African populations. Besides, it highlights the various identified barriers to diabetes management, behavioural change theories and relevance of culture to the public health.

Chapter 3 – Review of diabetes policy in the UK: Assessment and critical review of current diabetes policies and strategies in the UK for diabetes. Besides, this chapter will be looking at the ways of improving the quality of diabetes intervention programmes and strategies, and involvement of the lay people’s cultural belief and perspectives in the policy process.

Chapter 4 – Methodology: describes the methodological approaches and design adopted for the research, and the methods of data collection as well as the techniques used in the data analysis and interpretation of the study findings.

Chapter 5 – Research findings: presents the major findings from the study. It focuses on the results from interviews with people living with T2D among BsSA communities, HCPs and policymakers

Chapter 6 – Discussion: Outlines the specific factors and discusses the principal findings of the study, bringing together the results from the empirical work and relationships with relevant literature. These also include the theories and assertion explored in the literature review chapters.

Chapter 7 - Conclusion and recommendation: this is the summary of the whole research identifying the achieved research aims and objectives. The different contributions that the research project has made to knowledge, theory and its implications for diabetes policy, prevention and management programmes are subsequently presented in the latter part of the chapter. The final section of this chapter shows the reflection on the study and makes recommendations for future research.

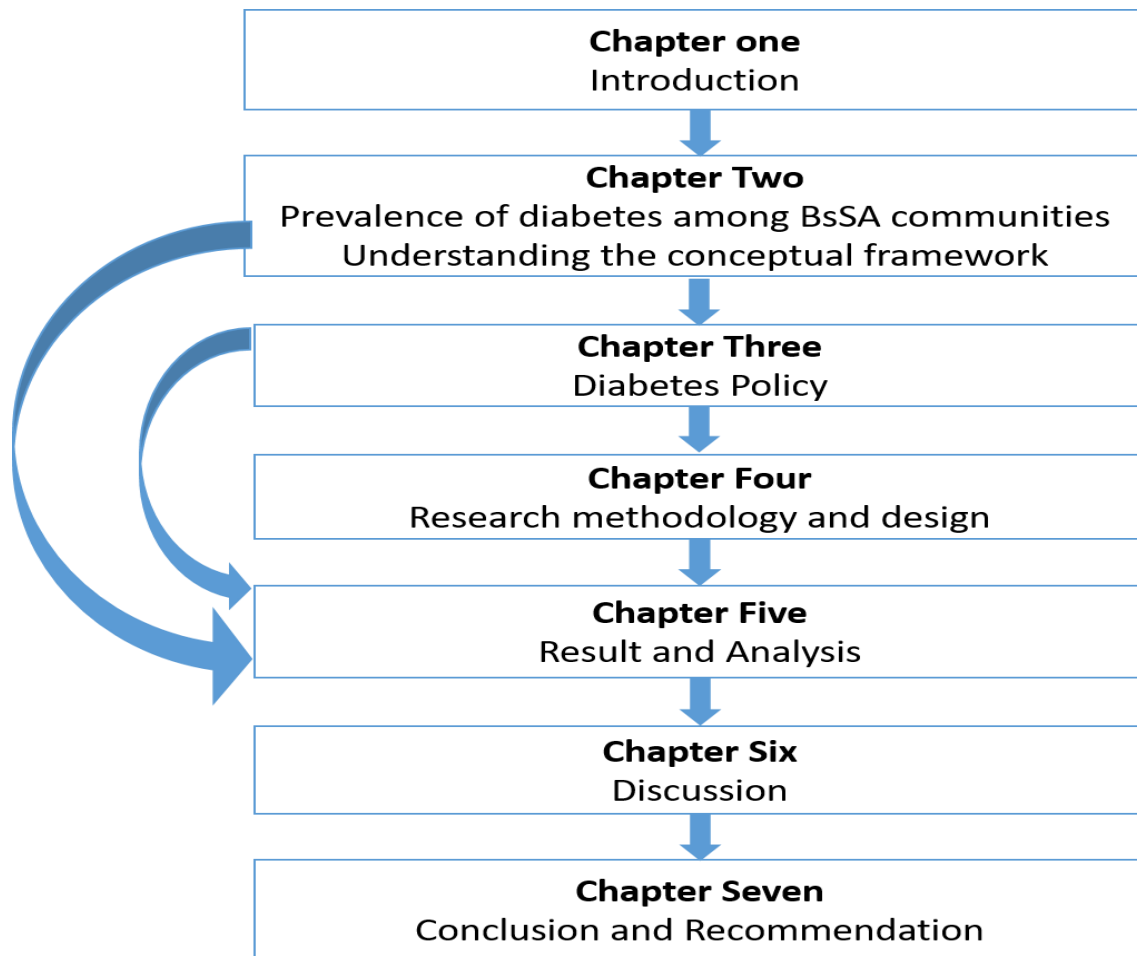


Figure 1.5. Schematic diagram of the thesis structure

1.10. Summary

In summary, the motivation for this research comes from the interest in health promotion and health awareness for people with diabetes among the BsSA communities. The study proposed that lay narratives, cultural values, and health beliefs within the diabetes intervention framework would help to improve self-management of diabetes, health-related quality of life, reduce health disparities and inequalities and lower health care costs.

The study would provide actionable recommendations to the appropriate public health officials and decision-makers about how to provide efficient health services and communal

support to BsSA communities. In addition, recommendations would be made to policymakers about the integration of cultural values and health beliefs into the mainstream health intervention services and management measures for T2D.

CHAPTER 2

REVIEW OF LITERATURE ON DIABETES PREVALENCE AND SELF-MANAGEMENT AMONG BLACK SUB-SAHARAN AFRICAN POPULATION IN ENGLAND

2.1. Introduction

This literature review was conducted to explore the current literature related to this study, mainly looking at diabetes prevalence and some of the contemporary cultural issues around self-management and health-seeking behaviours among the Black sub-Saharan (BsSA) communities in the UK. Considering Type 2 Diabetes (T2D) as a multifaceted public health issue, the need for an improved self-management behaviour, positive health outcomes among high-risk population like the BsSA communities and culturally embedded practices within the mainstream health system are highlighted as a key a key drive to encourage public health delivery collaborations that would make significant improvements in healthcare services. Public Health Outcomes Framework 2012 published by the Department of Health (DH, 2013) seeks to improve the health of the population by refocusing public health strategies around achieving positive health outcomes through collaborative intervention and initiatives for the population at risk of T2D and reducing inequalities in health, rather than focusing on process targets and clinical intervention. There have been a number of empirical studies showing poor access to health care, higher rates non-adherence to diabetes self-management practice, poor adherence to prescribed medication, unhealthy behaviours and obesity, especially among Black African population (including the BsSA communities) with diabetes compared to other people with diabetes in the UK (Higginbottom, 2006; Brown et al., 2007; Noakes, 2010; Abubakari et al., 2013). Therefore, it is important to explore how the significance and role of

cultural factors on self-management behaviours, the risks associated with diabetes self-management, and how the treatment expectations vary among the BsSA communities.

This chapter, therefore, presents existing knowledge regarding the prevalence of diabetes among the Black African population in the UK, conventional and nonconventional approaches to diabetes self-management, existing treatment interventions, barriers and outcomes. It also presents a synthesis of the literature on various cultural factors influencing self-management behaviours, the role of healthcare providers (HCPs) and experience of living with T2D. The latter part of the chapter looks at the behavioural theories and conceptual framework underpinning the study. The chapter concludes by highlighting the relevance of cultural beliefs to public health, identifies the gap in knowledge from the reviewed studies, which was used to form the basis for this research.

2.2. Search strategies for literature review

Focused literature was undertaken for this chapter through a comprehensive search of books and articles (including secondary resources) using key academic databases Applied Social Sciences Index and Abstracts (ASSIA) and Scopus databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane library, google scholar and the worldwide web. I undertook an extensive search using these databases to identify and capture relevant literature on T2D, T2D among BA population, cultural practices and self-management behaviours among the BsSA communities, diabetes policies and intervention strategies in the UK, from the year 2000 to 2018 inclusive. This time frame was important for the literature search as it helps to capture a full range of literature relevant to the research topic, to provide a concise thematic summary of current knowledge and to establish the current gap in knowledge. Specific terms and keywords such as Black and Minority Ethnic (BME) groups

and Black African population were used for the literature search due to the limited literature on diabetes self-management among the Black sub-Saharan African communities (BsSA). Article referring solely to Type 1 diabetes (T1D), scientific analysis of T2D intervention and clinical treatment of T2D or any other health issues associated with the researched population were excluded from the literature search on the basis that they were not relevant to the research topic and the objectives of the study. It is also important to note that the literature search and secondary data used in the identified literature were annually updated to capture any relevant new publications and information published after the initial literature search. The literature review presented here includes all relevant publications arising from this search process available at the time of the study.

The review aimed to identify, examine and provide a thematic overview of the basis of intervention for diabetes self-management among BsSA communities in the UK and the empirical evidence related to the prevalence, treatment choices and level of access that influence the engagement of BsSA with T2D with self-care. Besides, it identifies and evaluates studies on knowledge and perceptions of self-managing T2D, health seeking and culturally related behaviours that impact on intervention outcomes. Also, this literature review identifies the effectiveness of self-management support for type 2 diabetes, and perspectives of the BsSAs' living with T2D and healthcare professionals (HCPs) on self-care and self-management support provisions. The included studies were reviewed and critically analysed to illuminate the knowledge gap and justify the relevance of the current study. It is suggested that understanding the lay narratives of cultural and health beliefs and impacts on diabetes self-care that is rooted in social and community perspectives may provide a solution to the challenges of policy focus on T2D management behaviours. Understanding the root causes of the prevalence of T2D among high-risk communities such as the BsSAs, beginning

with exploring the people's cultural environments, their perceptions of ill-health and healing, and the complex cultural and health belief issues that influence their health behaviour can create a better process for health intervention and improved health outcome.

The review is structured into different sections and subsections for a comprehensive understanding of the research topic: the prevalence of T2D among the BA population, response to treatment interventions and delivery outcomes among the BsSA communities and a critical review of the beliefs and socio-cultural context of diabetes self-management. The latter part of the literature review covers the critical analysis of the diabetes self-management programmes outcomes in the UK, behavioural theories underpinning the study and establishing the relevance of cultural beliefs to public health. It then proceeds to look at the theoretical debates on the various National strategies and policy development for T2D intervention in the UK and implications for redesigning with the view of integrating cultural values and health beliefs into a diabetes intervention programme.

2.3. T2D among Black African population in the UK

2.3.1. Prevalence of diabetes among the Black African populations in the UK

This theme focuses on the prevalence and occurrence of diabetes among Black African communities in the UK. It will be providing an overview of previous and recent studies on the prevalence rate, mortality rate and burden of diabetes to the health care system and health expenditure in the UK.

The incidence of Diabetes, which is a significant public health issue, varies disproportionately among various ethnic minority populations. It is particularly more

prevalent among the Black and minority ethnic (BME) group (Diabetes UK, 2012c; Tillin et al. 2012; Public Health England, 2014; Harrison, 2014). People from Black Africa and African-Caribbean origin living in the UK are up to three times more likely than the white Europeans to be diagnosed with T2D (Whincup et al., 2010; Diabetes UK, 2012a; 2012b; NICE, 2012b; Tillin et al., 2013). Also, the SABRE (Southall and Brent Revisited) study found that nearly half of the people of Black African and African Caribbean origin will develop T2D by the age of 80 (Tillin et al., 2013). According to the Diabetes UK (2014), Black African people are not only at risk of having T2D, but they are also less likely to seek out guideline-based health information if diagnosed and adhere to quality treatment regimens to manage their health condition. This further exposes them to risk of developing other complications such as heart disease, stroke and kidney diseases. They are also more prone to other psychological complications such as depression and anxiety associated with this condition (Noakes, 2010; Carr, 2012). These diabetes-related complications could lead to a significant increase in morbidity and premature mortality (Harrison, 2014). Similarly, previous studies have reported that older people and those of a lower socioeconomic group among minority ethnic groups are more at risk of having diabetes (Ewles, 2005; NICE, 2012a; Sharma et al., 2014). The evidence that there is a higher prevalence of T2D among BME groups is now substantial.

Primary risk factors for T2D

Different risk factors have emerged for developing T2D. Previous research suggested that the Black African community has poorer health outcomes and high incidences of T2D (Abubakari et al., 2013). Abubakari et al.'s (2013) study identified that ethnic differences in the prevalence of diabetes might be explained through differences in knowledge-perception and disparities in the general distribution of behavioural or social risk factors such as

unhealthy dietary practices and weak health knowledge among this ethnic group. Similarly, Agyemang et al. (2009) argued that evidence and reports about health inequalities among minority ethnic groups and the increased risk linked to the increased prevalence of T2D among the African population could be generated through a range of complex and interrelated factors, including genetic, socioeconomic and cultural factors. Several studies have shown that socioeconomic factors and status (such as age and employment) mostly determine health inequalities and excess risk of diabetes among African people compared to other white European population (Smith et al., 2003a; Whincup et al., 2010). Other factors identified are environmental factors and socio-demographic factors such as age, gender, marital status, educational level and income level (Jenum et al., 2005; NICE, 2012a; Diabetes UK 2013a). T2D has also been linked to poor diet and lack of exercise among the Black African population, both of which are more likely to occur in low-income households and those that live in areas of high deprivation (Higgins and Dale, 2009; Carr, 2012; AHPN, 2013). However, biological factors and variations in genetic predisposition have also been reported as the underlying factor in the prevalence of T2D and general distribution of behavioural risk factors among Black African populations, such as the unhealthy dietary practices other studies have reported (Kirk et al., 2006; Tillin et al., 2013).

Obesity has been identified as a significant contributing factor to increased insulin concentration and decreased insulin insensitivity among people diagnosed with T2D (McCormack and Grant, 2013; Diabetes UK, 2014). It accounts for 80%-85% of the overall risk of developing T2D especially among the Black African and Caribbean populations (Diabetes UK, 2014). Similarly, Tillin et al. (2013) study demonstrated that the risk of T2D among people of Black African origin increases with increasing levels of obesity. However, men were reported in the SABRE study to have less central obesity and favourable lipids, less

insulin and high prevalence of diabetes among African population (Tillin et al., 2013). This suggests for a further study to examine other factors influencing the prevalence of diabetes among the African population in the UK (Tillin et al., 2013).

Furthermore, people from the Black African community are more susceptible to the risk of diabetes because of cultural beliefs and practices that influence health choices (Greenhalgh et al., 1998; Agyemang et al., 2009; Johnson et al., 2011). For example, traditional diets and other sedentary lifestyle being the norm - rather than active exercise. Cultural explanations of diabetes prevalence among Black African population becomes observable and evident when health beliefs and behaviours associated with the ethnic group concerned is established and recognised as a causative factor, especially for people whose beliefs embedded in their culture (Oldroyd et al., 2005). Brown et al. (2007) and Stronks et al. (2013) suggested that cultural beliefs and religion should be considered by HCPs when treating people with diabetes individually as these factors have a significant influence on the health patterns and behaviours associated with diabetes management, especially among African populations. Similarly, studies on health beliefs of African people with diabetes have also been reported in other European countries, US, Canada, Australia and Denmark (Rahim-William, 2011; McCormack and Grant, 2013). Data from other studies in the US indicates that people of African origin with diabetes have poorer diabetes control outcomes compared to the general population (Kirk et al., 2006; Chow et al., 2012). There have been reports about the knowledge gap on the belief of the causes and treatment of diabetes and its complications, behavioural lifestyle, and less consistent self-management of diabetes (Swelieh et al., 2014) and how this can be influenced by cultural beliefs and norms. These give the impression that different types of causative factors explain how Africans are being affected by diabetes in the UK compared to the general population.

Previous studies have established that cultural dietary and traditional cooking practices can contribute to an increased risk of diabetes among minority ethnic group, including Black African population (Brown et al., 2007; Carr, 2012; Weightman et al., 2013). Brown et al. (2007) study findings show that most traditional African diets are high in sugar, salt or fat which can result in weight gain or obesity. However, cultural values and perceptions of what constitutes a healthy weight can also be a factor in the belief system (Brown et al., 2007). One of the risk factors identified for T2D is the accumulation of fat (adipose tissue) around the abdomen and waist area, particularly truncal, which genetically affects some African peoples (Weightman et al., 2013). Due to different dietary patterns, lack of participation in physical activity to burn off fats, and other daily cultural activities, it could be argued these are possible causes for lack of effective management of diabetes (Agyemang et al., 2009). Moreover, this has led to a critical gap in knowledge about diabetes prevalence and management among Black African populations in the UK. Also, people from the African populations and other minority groups have been reported to be more likely to live in low-income households than the white European populations, due to increased levels of unemployment (Higgins and Dale, 2009). They are also more likely to live in areas reported for high deprivation, which increases the risk of obesity and T2D (Higgins and Dale, 2009). This simply identifies that the more risk factors presented among people with obesity, the greater the chances of the person developing T2D (NICE, 2011a; PHE, 2016b). Thus, the difference in prevalence of T2D among people from Black African origin as compared to the white European population has been attributed to the complex and unclear interplay of genetic susceptibility and environmental factors.

On reflection, while studies have compared various factors responsible for health inequalities among the different minority ethnic groups in the UK, evidence has shown that Black African

populations experience poorer health outcomes and management and are more susceptible to the risk of T2D than the general population (Abubakari et al., 2013). However, these studies explained only part of the risk factors for T2D, suggesting that other factors such as culture and health beliefs are yet to be extensively explored among Black African populations in the UK in order to determine how these factors influence self-management behaviours and health outcomes among this minority ethnic group. It is also important to investigate the illness perception of diabetes and linked health experiences among Black African populations with diabetes self-management to explain some of the observed disparities in health outcome and diabetes self-management behaviour compared to other minority ethnic groups.

2.3.2. Diabetes treatment and management among Black African communities in Nottingham and related literature

Nottingham has been categorised as one of the cities with high prevalence rates of T2D in England with the prevalence rate of 5.5% of the diagnosed adult population and compared to 6.5% in England in 2015/16 (estimated prevalence is 7.2% compared to 7.3%). This implies that within the City of Nottingham, only an approximated 74% of people with diabetes have been diagnosed (see figure 2.1) compared to 77% nationally (PHE, 2017a). The estimated total prevalence of diabetes in the NHS Nottingham City CCG is 7.5% (diagnosed and undiagnosed) and estimated to increase to 8.6% compared to 9.7% in England by 2035 (PHE, 2016a) if the current trends in obesity rise continue among the population (PHE, 2017b). The estimation shows that the prevalence of diabetes in Nottingham is expected to increase predominantly because of the increasing level of obesity by 3% every 5 years (PHE, 2016b) and a higher level of migration of Black and minority ethnic (BME) groups, including the Black African population to Nottingham (Nottingham Insight, 2016). According to the Nottingham City Joint Strategic Needs Assessment report (Nottingham Insight, 2016), life

expectancy for persons with T2D in Nottingham is reduced by at least 5-7 years compared to the life expectancy reduction of 6-10 years for people with T2D in the whole UK population.

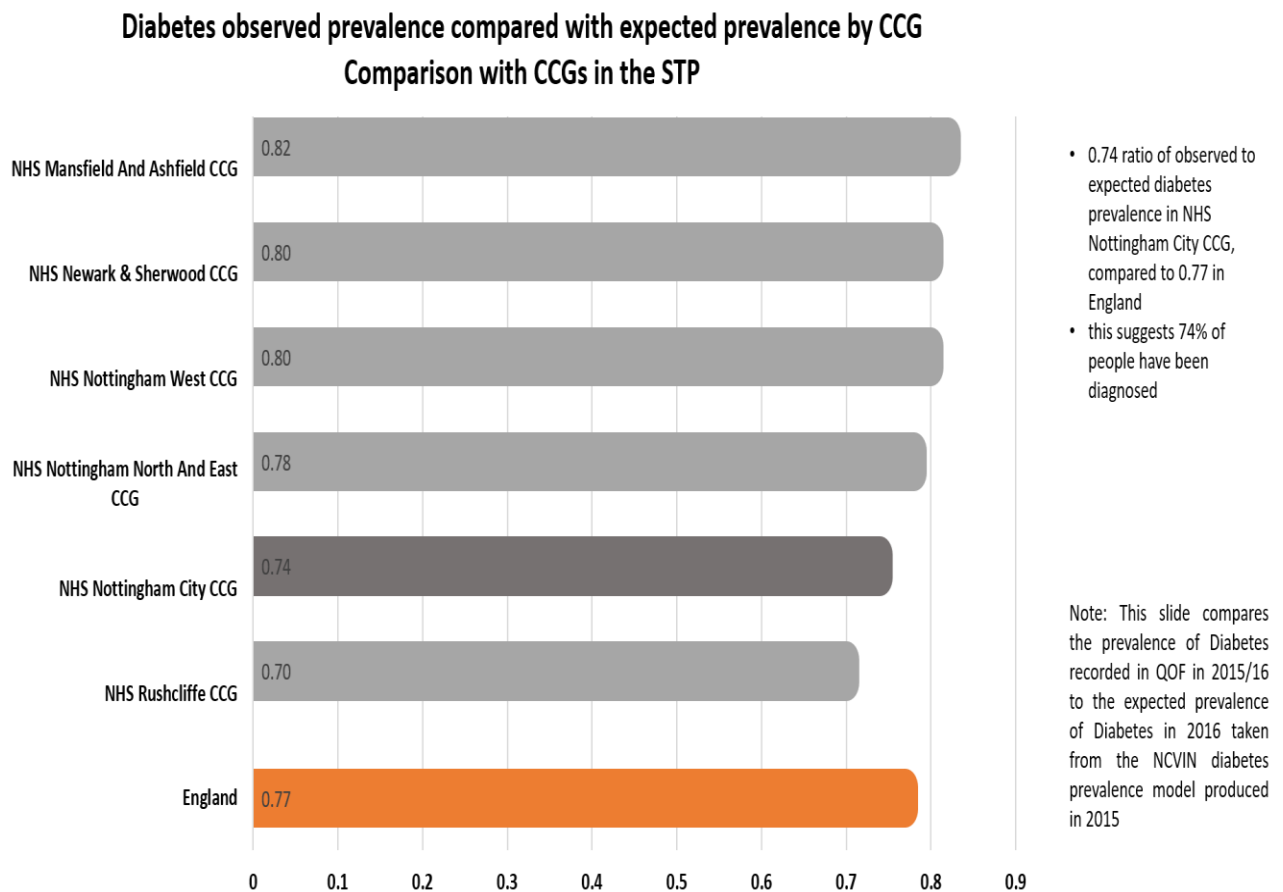


Figure 2.1. Prevalence of diabetes in Nottingham compared to other cities

(Source: PHE, 2017a)

Various diabetes prevention, treatment and management programmes managed through Quality and Outcome Framework (QOF) and coordinated by the primary care in Nottingham, have been implemented for diabetes control and supporting awareness of lifestyle risk factors targeted at communities at risk for behavioural change (Nottingham Insight, 2016). Some of these programmes are obesity and weight management, NHS Health Check, Changemakers for Heart Health, Structured Education programmes for T2D, Diabetic Retinopathy

screening, Community Diabetes Nurse service, telephone outreach service ('Own Health') and Medicine Management support (Nottingham Insight, 2016). However, health outcome and the risk of complications for people with T2D have become a major health inequality issue, especially among the Black and minority ethnic group in Nottingham making health intervention and education essential (Nottingham Insight, 2016). The Nottingham City Joint Strategic needs assessment recommended the need to investigate other facilitators that could be used to tackle the predicted increase in diabetes prevalence and other major health inequalities issues among the BME population in Nottingham (Nottingham Insight, 2016). Hence, it is established that there is a need for further extensive research to help understand and provide new insight into the future direction for managing T2D among Black African populations (Bashir et al., 2016).

Different studies have explored diabetes treatment and management system in Nottingham between different minority ethnic groups identifying the rate of non-attendance for treatment, lack of adherence to prescribed regimens and a decrease in participation in diabetes intervention programmes (Brown et al., 2007). Brown et al. (2007) study identified various factors, such as migration in the UK, knowledge and understanding, mistrust in the value of advice and treatment as potential inhibiting factors to ineffective adherence to diabetes management among the African Caribbean. However, this study was limited to the African Caribbean communities alone, and it does not provide an in-depth understanding of how culture and health beliefs affect diabetes self-management among BsSA populations in Nottingham. Similarly, David and Kendrick (2004) study described the various processes and access to diabetic care among minority ethnic group in Nottingham. Nevertheless, David and Kendrick (2004) study revealed no process of intervention through a cultural understanding of individuals living with diabetes and the impact on diabetes self-management behaviour.

Also, the study was only compared to access to health care provided to White and South Asians with no information about the Black African population. Although it has been argued that BME community in Nottingham's poor diabetes management outcome may be attributed to differences in access to health care, adherence to treatment and medication, and deprivation (Brown et al., 2006), what is less understood is how peoples' culture and health beliefs can serve as a determining factor for diabetes self-management and how this can be used as an intervention measure for people from the BsSA communities.

To conclude, the majority of these studies had little information to identify culture and health beliefs as an indicator or modifying factor and how this can be used as a positive intervention measure to help improve health outcomes among BsSA communities and how this can implement changes to the diabetes care service in the UK (Abubakari et al., 2013). It is therefore important to note that a further study to explore the impact of sociocultural factors that will increase the understanding of the experience of culture and beliefs among Black Minority ethnic population in the UK is essential.

2.4. Response to treatment intervention and delivery outcome among the BsSA communities

2.4.1. Uptake of, and access to diabetes care and health service

Studies have suggested that interactions with the health care services can have a significant effect on a person's understanding of living with a chronic illness (Hart, 2001) through the meanings attributed to the disease and health care delivery (Lawton et al., 2005). Differences in and reduced access to specific health care services among the Black minority ethnic population in the UK presents a major challenge the health system, HCPs and policymakers

in terms of achieving equitable access and service delivery (Atkinson et al., 2001; Szczepura, 2005; Randhawa, 2007). According to Szczepura (2005) and Marmot (2010), poor access to adequate health care contributes significantly to the increased level of mortality and morbidity, greater diseases and poorer health outcomes among Black and minority ethnic group. However, the overview and monitoring of disparities in health care access for BME populations by the NHS have proven difficult (Szczepura, 2005). Nevertheless, the service quality indicators for the analysis of patient satisfaction survey showed significant differences in health and quality of care among minority ethnic group in the UK (CHI, 2004). Further studies in the UK have shown that there are various factors and evidence to explain the disparities in access to health care in terms of uptake, the process of care and quality of care among Black minority populations in the UK (Szczepura, 2005; Scheppers et al., 2006). Szczepura (2005) review stated that people, based on diverse ethnic groups and cultural backgrounds might respond differently to health care because of their health beliefs and behaviours that may not comply with biomedical practices. On the other hand, Schoenberg et al. (2009) argued that knowledge gap on illness perception of people and how they see themselves as persons and not as patients undermine the HCPs' ability to appropriately address the issue of uptake of care and disease prevention at an optimal level.

Furthermore, Smith et al. (2003b) review identified limited knowledge about the awareness, availability of the health care system, poor understanding of the value of the preventive care and lack of acculturation of health education provided as other reasons why people from minority ethnic group have inadequate access to health care and services. The review showed that individuals might differ in their perception about illness severities and the urgency with which they need to seek help to avoid further complications (Brown et al., 2007). Similarly, Anderson et al. (2003) review reported that the absence of appropriate and effective

communication with a diverse audience and lack of materials developed and tested for specific cultural groups could prevent equitable access to health care for Black and minority ethnic population. Moreover, other studies suggest that inequalities in access to health care and differences in health outcomes in relation to diabetes management may be due subsequent lower rate of referral and GP consultation (Gill et al., 2007), fewer follow-up services (Mead and Roland, 2009) and longer waiting times for an appointment and referral, communication problems (APPGD, 2015). APPGD (2015) reported from their study that the majority of people reported that places for health care and diabetes education were only available for the people newly diagnosed with diabetes. Nevertheless, Wilson et al. (2012) suggested that it is important that a whole systems approach that incorporates integrated service and broader sociocultural factors is developed to improve patient's self-management and improved access to health care and provide equitable services. A previous study by Szczepura (2005) suggested that ethnic differences in access to health service could not only be reduced to socioeconomic factors; suggesting other sociocultural factors should be considered to measure the disparities in access to health care among the Black minority ethnic population in the UK and the need for cultural adaptation in service delivery. However, there is little information available to understand how sociocultural factors affect diabetes self-management and health outcomes in terms of access to health care services for Black and minority ethnic group.

The study concludes that despite the advances in prevention, treatment and management measures of diabetes, there are still records of the ethnic minority population having poor access health care.

2.4.2. Non-adherence to treatment, service care and health intervention

Several studies have reported the significance of the intervention; medically, socially, psychologically, and diabetes education in reducing the risk of diabetes-related complications (Nazroo et al., 2008; Khunti et al., 2012; Harvey, 2015; Huffman et al., 2015; APPGD, 2015). However, the prevalence of diabetes among Black and minority ethnic group remains high despite these interventions. According to Nazroo et al. (2008) study, the prevalence of diabetes among black and minority population in the UK could be related to lack of adherence or noncompliance with treatment regimens. It is also due to self-care behaviours, which consequently requires long-term lifestyle and behavioural changes.

Nonetheless, other studies have identified various factors that influence people's adherence to treatment regimens and behavioural change. Oldroyd et al. (2005) and Brown et al. (2007) stated that poor understanding of the severity of symptoms and basic knowledge or limited knowledge about management of illness provided to people with diabetes could affect the efficacy of their responses to treatment and management regimens. Similarly, Lawton et al. (2006) and Hanif and Karamat (2009) argued that non-concordance to medical treatment is common, especially among people with no symptoms of illness or having unpleasant side effects. In as much as self-management and adherence to medical treatment are the keys to good glycaemic control, some individual only considers using medical treatment based on the severity of the disease or symptoms (Harrison, 2014). According to Lawton et al. (2006) study, people disengage from using their prescribed medication, alter their dosage if they still feel unwell, or believe that continued use of the medication could cause more damage to their health. Consequently, Hanif and Karamat (2009) further suggested the need for a better understanding of perspectives of treatment and health management to improve adherence to medical treatment.

People living with T2D may have limited knowledge of managing illness successfully when traditional diet and lifestyle is not included in health management regimens and dietary advice provided to them (Oldroyd et al., 2005; Brown et al., 2007; Everson-Hock et al., 2013). Besides, poor knowledge about the availability of service and mistrust the value of treatment and preventive care may contribute significantly to the lack of adherence to treatment and services (Oldroyd et al., 2005; Brown et al., 2007; Winkley et al., 2015). Whilst participants from Oldroyd et al. (2005) study, claimed that they were not given the same quality of service by the NHS as white people in the UK, Brown et al. (2007) study identified that people found it challenging to integrate dietary advice with their traditional diet, and found the information to be at odds with their health or cultural beliefs. Oldroyd et al. (2005) reported that while many people, including those born in the UK, felt that HCPs did not consider the individuals' dietary preference when giving health advice. Others were concerned about chemicals in their medications; thinking they may cause more damage to their health condition. There is more preference for natural and alternative treatments due to treatment benefits and efficacy of herbal remedies, which people tend to find more accessible (Oldroyd et al., 2005; Harrison, 2014). Similarly, Mosnier-Pudar et al. (2010) stated that anxiety and fear during diagnosis could make people overwhelmed, feeling that diabetes is a heavy burden on every aspect of their life. Moreover, obsessions with different diet because of an inability to stick to one diet have also been identified to lead to depression and anxiety (Mosnier-Pudar et al., 2010). Harrison (2014) argued further that an individual's attitude towards adherence to medical treatment could be because of misconceptions about being harmful if used long-term with other drugs or a specific food.

Furthermore, inadequate provision of efficient and integrated health education to help people with T2D to manage their health and illness has been reported to pose a major challenge to

diabetes intervention progress and implementation in the UK. Recent studies assessing the effectiveness of diabetes structure education programme (X-PERT) and the cost of savings on delivery suggest that the programme improved lifestyle, health knowledge and the psychosocial effect on PLWD (Deakin et al., 2006, Khunti, et al., 2012). Although the programme was reported to offer a cost-effective strategy; adding to the value of treatment and management of diabetes, which significantly improve health and quality of life (Gillett et al., 2010), other studies have reported nonadherence to the structured education sessions, partly because of lack of awareness (Ashtarian et al., 2012), lack of information and benefits of programme (Winkley, 2015; APPGD, 2015) and lack of motivation or support (Ockleford et al., 2008). On the other hand, the APPGD (2015) report discussed that the expression of the programme as a '*structured education*' or '*medically oriented*', could have a contrary interpretation to people with diabetes who are not formally educated and could also result in nonadherence to treatment or service advice. The report further suggests more user-friendly and comprehensive expressions that allow people with diabetes, interpret health programmes as being interactive, engaging and skills-based learning programmes, which assist people to self-manage their health condition (APPGD, 2015). Despite the established benefits of diabetes-structured programmes, the evidence of non-adherence and low rate of participation in intervention programmes suggest reasons for not just prevalence of T2D but also the lack of uptake of healthcare and symptoms managements, especially among the Black African population.

2.4.3. Non-acceptability of health interventions

Several studies suggest that there are other factors and facilitators that influence an individual's approach to lifestyle behaviours and acceptability of health intervention (Johnson et al., 2011; Everson et al., 2013). The studies have suggested that acceptance of diabetes

treatment intervention was significantly dependent on personal and individual commitment behaviours. Family and work commitment was considered as a possible reason for the lack of acceptability of certain health intervention (Johnson et al., 2011). Johnson et al. (2011) review identified people's lack of time to carry out prescribed activities due to child care and other family commitment and working longer hours to fend for the family, limits acceptance and participation in certain diabetes-related intervention programmes. In addition, it was identified from the review that due to limited financial resources, women tend to prioritise their children's need for themselves (Johnson et al., 2011). Similarly, Coleman et al. (2008) and Everson-Hock et al. (2013) studies recognised that commitment and responsibility to other social activities could make people not to accept specific health-related interventions. Equally, others may believe that events around the home and their social life activities are sufficient to manage their individual health (Everson-Hock et al., 2013).

Nevertheless, Noakes (2010) argued that people with T2D are most likely to accept health intervention and participate in treatment regimens because of personal experience of the benefits and information obtained from friends and families with the diabetes-related condition who perceived the intervention or treatment to be effective. On the contrary, Kumar et al. (2006) and Chang et al. (2010) argue that people with T2D are most likely to accept other natural alternative treatment measures if seen effective as recommended by friends and family due to mistrust in the value of health advice or information provided by the hospital during and after diagnosis. Moreover, Netto et al. (2007) and Noakes (2010) suggest that cultural influence among the Black and minority communities in the UK could be responsible for individual response to acceptability and participation in health intervention for behavioural change. Lawrence et al. (2007) and Netto et al. (2007) study emphasised that identifying and intervening in certain cultural risk factors to raise the cultural sensitivity of

healthcare delivery among Black and minority ethnic group could decrease the prevalence of T2D and acceptance of health intervention in a long-term.

2.5. Cultural and health beliefs

Culture and health beliefs have been central to social science and public health research, and this is especially so in the field of anthropology and sociology of health and illness (Hahn and Inhorn, 2009). Recent studies have discussed sociocultural differences and other factors that influence social behaviours among different ethnic groups in the UK (Brown et al., 2007; Abubakari et al., 2013; Patel et al., 2015). According to Uskul (2010) and Nettleton (2013), the cultural environment shapes an individual's attitude and behaviour towards health and illness. This section will be describing a brief overview of the concept of culture and the understanding of health beliefs, the trends of cultural practices in diabetes treatment and management, the interacting factors and the impacts on diabetes self-management among Black African populations in the UK.

2.5.1. Understanding culture and health beliefs

Culture is defined as collective and shared knowledge, beliefs, values, customs and habits associated with health-related behaviour among a group of people, religion or ethnicity within a society (Pasick et al., 1996; Kulkarni, 2004; Nam et al., 2011). Similarly, Helman (2007, p. 2) defines culture as “... *an inherited 'lens', through which an individual perceives and understands the world that they inhabit and learns how to live within*”. Culture helps to understand the beliefs, attitude and behaviour of others, avoiding stereotypes and predispositions that can undermine a health intervention (Lucas et al., 2013). On the other hand, Hanif and Karamat (2009, p. 27) define culture as “*a complex interaction of multitudes*

of factors that give a people an ethnic belonging and also has an impact on their lifestyle and predisposition to chronic disease". Culture consists of derivatives of experiences and is passed through individuals, and through this process, it becomes personalised and meaningful (Winkelman, 2009). Culture impacts upon certain cognitive structures that mediate people's interpretation of physical health and emotional states of mind; for instance, the same symptoms may be seen to be indicative of different illnesses depending on the cultural perspective in which they are being considered. The biomedical perspective of health which focuses on the physical dimension of disease, particularly in the case of T2D, is perceived to exclude the social, psychological and cultural context of the illness experience (Helman, 2017; Macaden and Clarke, 2010). Therefore, to separate culture from a person's experience of health is to eliminate the core meaning of culture, since culture exists only through a person and the world around the person; it is the person who brings culture alive and gives it a reality based on their experience. Culture differs in various ethnic groups based on their collective interpretation and approach to life. For example, the Ubuntu culture which is common among the BsSA communities emphasises the importance of the collective knowledge of a community to the existence of an individual lay belief system. It reflects the collective sense of being of an individual, emphasising the identity-sustaining ties of an individual through interconnectedness and togetherness with other people within the community (Nyashanu, Serrant and Chazovachii, 2017). In some cultures, family honour and interest are highly important than the individual's experience of health and illness, which then affect individual decisions on treatment acceptance and compliance.

The term culture can be used to describe different cultural practices and cultural belief terms that are mostly used interchangeably to describe and explain ethnic behaviour disparities in health outcomes, response to treatment and people's perception of illness (Lucas et al., 2013).

Lucas et al. (2013) suggest that exploring and examining people's cultural and social norms in health intervention helps to understand the motivating factors for behavioural change. Cultural issues play a significant role in an individual's compliance with health education and treatment regimens depending on the individual's level of understanding of the interaction of medicine with the body and experience with the illness (Warwick-Booth et al. 2012). The extent to which an individual perceives the importance of health education and treatment as having cultural relevance to them can, however, have a significant effect on the acceptance and the willingness to fully manage their illness on their own. (Helman, 2007). For example, Greenhalgh et al. (1998), Lawton et al. (2008) and Patel et al. (2016) study show how cultural understandings inform South Asians dietary practices and perspectives about physical activity and self-management strategies. It is reported from these studies that current diabetes services are operating within a typically Western medical framework and, not fully considering other cultural understandings and beliefs that inform people's health behaviours. Culture defines an individual's belief system that explains what causes illness, the consequences of diagnosis, how it can be cured, treated or managed. It also defines the role and expectations of the treatment process, whether individual, family, community or religion (Warwick-Booth et al., 2012). Hence, the question of how cultural values, differences and understandings are recognised in a healthcare context.

The influence of cultural influence on health behaviour has been recognised as crucial in the health intervention process among groups that are particularly the most at risk of certain diseases and illnesses (Nam et al., 2011; Lucas et al., 2013). For instance, uptake of the Ubuntu scheme to create awareness about the risk factors and stigma associated with HIV and sexual health provides a cultural platform for reducing HIV stigma and improving health-seeking behaviours among the BsSA communities. Embedding Ubuntu scheme in the sexual

health activities emphasised the importance of including the intra-community cultural knowledge and beliefs in health initiatives related to the BsSA community (Nyashanu, Serrant and Chazovachii, 2017). The Ubuntu scheme stresses on community cohesion and interconnectedness for the purposes of individuals' empowerment and improved health behaviour. Several other studies have also reported the impact of culture on health education and its association with the increased prevalence of diabetes among minority ethnic population and as dominant risk factor for unhealthy behaviour in diabetes self-management (Oldroyd, 2005, Carr et al., 2012; Adejoh, 2014; Patel et al., 2015). Most of these studies call for a change in the way services are delivered to ethnic minority groups, including the BsSA communities but also recommend the involvement of these communities in the provision of culturally sensitive programmes that would enable them to adopt positive attitudes to disease prevention and management.

Health beliefs on the other hand are assumed to be rooted in broader socio-cultural contexts describing the level of knowledge an individual has on health and illness (Greenhalgh et al., 1998; Lucas et al., 2013). It explains how people with diabetes understand and interpret the management of their health condition in the context of their own opinion and position. For example, health beliefs could be related to traditional and religious beliefs based on people's perspectives about God (spirituality as a source of support or belief about health and illness) and the act of living with illness (Grace et al., 2008; Johnson et al., 2011). Similarly, Everson-Hock et al. (2013) and Patel et al. (2015) found that people's traditional and cultural beliefs sometimes determine their different understandings about the causes of diabetes and its complications and could hinder positive self-management behaviours. While some people's belief that awareness of lifestyles and behavioural factors, such as diet and physical inactivity, influence the risk of diabetes, others believe that their exposure to European

lifestyle and culture worsen their pre-disposition to a healthy lifestyle (Brown et al., 2007; Johnson et al., 2011). Brown et al. (2007) suggested that helping people in the African population manage their diabetes involves an understanding of their culture and belief system. Therefore, there should be a consideration for changes in service provision to understand, accept and incorporate African people's health belief to help improve self-management.

Furthermore, culture and health beliefs have been linked to the use of other health practices or remedies based on ancient traditions, beliefs and philosophies about health and healing (Lee et al., 2004). According to Kumar et al. (2006) and Chang et al. (2010) people tend to use other health remedies because of the perception of achieving treatment and healing through spiritual assistance and interventions was an important component of care presumed to counter the unkindness from supernatural forces. There is also the cultural belief that traditional remedies are more reliable than western medicine. Therefore, people used variety of treatments either alternative or complementary to biomedical treatments. Carr (2012) argues that to consider culturally sensitive information and advice for health intervention for individuals at risk of long-term disease, it is crucial recognising the use of other health practices such as alternative remedies in the treatment of certain health condition. Fisher et al. (2005) and Nam et al. (2011) concluded their studies by calling for further studies and understanding of culture in individual's perspectives and its functions within the sociocultural context of disease self-management and delivery of health intervention programmes.

2.5.2. Self-management

Self-management is an important aspect of self-care of a long-term chronic health condition, such as diabetes, which requires the encouragement, empowerment and education of people

to have the proactive management of it. Self-management necessitate individuals to have a sense of control over their condition in a proactive way, to reduce the risk of long-term complications (Funnel et al., 2011). Self-management is generally defined as an act of practising specific behaviours or undertaking specific action to reduce the physical, psychological and emotional impact of an illness regardless of whether an individual participate in any recommended health intervention programmes (Lorig and Holman, 2003). Self-management can either be day-to-day activities or done periodically, which sometimes can be referred to as self-monitoring. Thus, self-monitoring is a component of self-management that requires periodic assessment and observation of symptoms or treatment associated with an illness, for example, blood glucose monitoring test. Good self-management behaviours have emerged as essential components of a lifestyle or behavioural modification. This requires individual responsibility and actions directed towards self, community or environment to regulate one's functioning and health outcome in the interest of one's life; leading to integrated body functioning and well-being (Diabetes UK, 2009b).

2.5.3. Trends in cultural practices and health beliefs in diabetes self-management

Several studies have shown that diabetes self-management is culturally embedded. These studies acknowledge the importance of knowledge and understanding of other external social and cultural factors that determine individuals' management behaviour to an illness (Greenhalgh et al., 1998; Murphy et al., 2011; Patel et al., 2015). However, Patel et al. (2015) argued that cultural health beliefs and poor knowledge about diabetes, and its related complication hinders positive self-management behaviour and practices. On the other hand, Bean et al. (2007) argued that some Black African populations have greater knowledge about diabetes management gathered from their experience of having diabetes and the process of management. Bean et al. (2007) observed that people's experience with their health condition

could shape or have an influence on their perception of diabetes and enhance their health management behaviours and diabetes outcomes. Similarly, Abubakari (2013) emphasised that people's understanding and interpretation of health management and other actions and beliefs that pertain to health could be shaped by people's wider social and behavioural factors such as cultural context, health beliefs, structural location and environment, personal experience of life and social identity.

The impact of health beliefs and poor understanding of diabetes have been reported in various studies on self-management practices and behaviour (Brown et al., 2007; Stone et al., 2010). In the UK, health beliefs are rapidly becoming a major factor on people's adherence to treatment for T2D, and this may affect the health outcomes (Brown et al. 2007; Johnson et al., 2011). Brown et al. (2007) and Johnson et al. (2011) study discussed how health beliefs influence people's adherence to treatment and management regimens and this subsequently affects health behaviour and outcomes of people with diabetes in an African population.

Studies of health beliefs among Black African people with diabetes and the influence on treatment adherence and management have also been reported in other countries (Chin et al., 2000; Chlebowy et al., 2010; Rahim-Williams, 2011; Adejoh, 2014; Sherman, 2015; Brathwaite and Lemonde, 2015; Bockwoldt et al., 2016). Other studies have identified the negative impacts of non-adherence to treatment regimens and acceptance of other alternative therapies or traditional medicines to be as a result of the feelings of powerlessness over illness, fear, lack of access to health resources, struggle to maintain diet and nutritional changes, cost of medications, knowledge gaps, inability to link their behaviour with health outcomes, and lack of social and family support (Brown et al., 2007; Morrow et al., 2008; Marmot, 2010; Mosnier-Pudar et al., 2010; Nam et al., 2011). However, other studies have

reported faith, religious belief, fatalism and reliance on hope, as explanations for non-adherence to medical regimens and treatment choice in diabetes self-management (Johnson et al., 2011; Lucas et al., 2013; Patel et al., 2015). Similarly, Noakes (2010), Johnson et al. (2011) and Abubakari et al. (2013) described how health beliefs and culture of African people might lead to less effective self-management of their diabetes. Nevertheless, Brown et al. (2007) study further emphasised the need to explore further the influence of health beliefs and culture of people with diabetes in the black and minority ethnic group.

Although it has been established as a result of extensive research on diabetes management that minority ethnic groups are more susceptible and at a higher risk to have diabetes (Diabetes UK, 2016b) but what is less well understood is how individuals perceive the relationship between health intervention programmes implemented, the impact of individual's cultural beliefs and how HCPs and policymakers understand people's culture and health beliefs additionally for health intervention. According to Greenhalgh et al. (1998) study of diabetes health beliefs among British Bangladesh, successful self-management of diabetes requires the understanding of people's lifestyle, beliefs, attitudes and social network. The study further highlights the importance of considering a wider cultural context that drives people's behaviour and health decisions (Greenhalgh et al., 1998). Given the elevated risk of diabetes among the Black African population, a more in-depth explanation is needed to understand the underlying cultural practices and health beliefs on diabetes and the impacts on self-management behaviour and health outcome. Schoenberg et al. (2009) suggested the need to take people's views, experiences into account in terms of policy, and programmes so that they are appropriately developed and sustained in any health intervention.

2.6. Identified factors influencing diabetes self-management behaviours

Although there are various assumptions about how people with diabetes can self-manage their health condition, there are different barriers to people with diabetes actively managing their health conditions. People's lack of adherence to diabetes self-management recommendation can be attributed to different factors, which, if reflected upon and adequately managed can help to reduce mortality and disability because of complications, improve the quality of life and reduce health costs for individuals affected by the illness (Nam et al., 2011). Nam et al. (2011) study suggested the need for a greater understanding of culture and health behaviours, and the significance of culture within a socio-structural context as it relates to diabetes self-management behaviours. Health-seeking and self-management behaviours are specific responses to perceived ill-health, and it should be looked at within its cultural context since culturally recognised signs and symptoms and their associated interpretations influence related activities and interpretations. Although specific diabetes studies on health care behaviours among Black African communities may be limited, findings from many other studies on health care behaviour among other minority and ethnic groups have been used to guide the current study.

2.6.1. Awareness, knowledge, attitude and illness perception about T2D / Perceptions about T2D and illness causation

The perceptions of the definition of a healthy lifestyle, unhealthy lifestyle and health-seeking behaviours vary by individual's culture and experiences of health, and healing (Nam et al., 2011). Over the years, several studies have specified range of cultural knowledge and attitudes towards diabetes, which in turn affect the way people perceive the need for, and importance of, treatment and prevention. It can also affect the self-management of their health condition (Nam et al., 2011) and adherence to treatment regimens (Brown et al., 2007;

Abubakari et al., 2013; Lucas et al., 2013). Nam et al. (2011) highlighted that people's knowledge and attitudes could have an impact on management when people perceive treatment as a personal failure and deserve punishment for not managing their health properly or it could be a fear of daily treatment, which could mean life is restricted or delimited from enjoyment. Some knowledge could also be affected by concern about medical treatments given, as some may believe that medical treatment like insulin injection can worsen health condition and could even cause further complications to their health (Nam et al., 2011). Morrow et al. (2008) emphasise that the feelings of denial can influence people's knowledge about self-management and acceptance of illness diagnosis. Similarly, Everson-Hock et al. (2013) argued that people's behavioural change for the effective health management might be influenced by their lack of perceived seriousness of the illness or lack of perceived susceptibility to diabetes complication.

However, other factors and biomedical understanding have been identified among the Black minority ethnic group to explain T2D causation. Within the African community, the onset of T2D is attributed to a range of external influences and risk factors, including, family history, heredity, dietary factors, such as western diet and sugar intake, and social isolation in the community (Tillin et al., 2012). SABRE study identified that the onset of T2D is often preceded by an increase in insulin resistance, which is also attributed to weight gain and obesity (Tillin et al., 2012). The study found that higher body fat levels, especially around the waistline, and resistance to insulin explained the risk of T2D among Black African women. Nonetheless, this only described part of the risk for Black African men, suggesting that other factors may play significant roles in the onset of T2D among this ethnic group (ibid). Nonetheless, the study reported that the awareness of the risk factors associated with T2D among people from BsSA community is unusually low.

While the evidence on the perception of T2D and related risk factors may be somewhat limited, some studies have shed light on how certain Black minority ethnic group, including BsSA communities, understand diabetes illness and other observed limitations in the management of the disease. While some identified disparities in management behaviours because of cultural values or traditional health concepts, others draw upon western influence and lifestyle as a factor to explain illness and health behaviour. Brown et al. (2007) study of health beliefs of Afro-Caribbean people living with T2D identified the significance of knowledge and understanding among African population and how that influence diabetes management behaviour. Although the study perceived that most participants have basic knowledge of certain lifestyle factors that predispose individuals to T2D, some felt that the illness was aggravated by adapting to the western lifestyle and the majority have a limited understanding of how to manage their disease effectively (Brown et al., 2007). Similarly, Abubakari et al. (2011) cross-sectional study of the relationship between, diabetes-specific knowledge, illness perception, and self-management of diabetes and metabolic control outcomes for diabetes among African origin patients in the UK considered the association of health behaviour and outcome with poor self-management. The results from the study revealed that, of all 359 people with diabetes who participated in the study, the perception of diabetes severity was associated with poor self-management in both African origin and European origin. In addition, perceived personal control over diabetes was identified as key determinants of the disparities in self-management behaviours among people of African and European origin (Abubakari et al., 2011).

Although specific studies provided insight into individual's diabetes-specific knowledge and belief, it was considered that different illness perceptions and ways of management could also

be associated with individual's geographical location, religion, culture, age and other social factors (APPGD, 2015; Nettleton, 2013). Abubakari et al. (2013) study found that different demographic characteristics such as origin, culture, population, predicts people's adherence to self-management recommendations. A demographic questionnaire was used in their study to measure diabetes-specific knowledge, self-management and illness perception utilising a diabetes knowledge test (DKT), the summary of diabetes self-care activities (SDSCA) and the revised illness perceptions (IPQ-R) individually. Abubakari et al. (2013) study discovered significant differences in knowledge, perception between different ethnic groups in the UK, with White-British having more specific and detailed knowledge of diabetes compared to the Black-African population in the UK. Individual personal experiences of the illness sometimes determine the interpretation of the self-management (Cameron and Moss-Morris, 2010; Abubakari et al., 2013). For example, dietary intake or practices can have a significant meaning to people's social, cultural and personal values, which may have no or little consequence or impact on an individual's health (Nettleton, 2013). There are a particular set of people that presumed that certain diseases are more susceptible to cause damage to health, death or further complication than others and these perceptions partly influence disease outcome and control (Greenhalgh et al., 1998; Abubakari et al., 2013; APPGD, 2015). Abubakari et al. (2013) discussed further that despite the weak knowledge of diabetes and misconception about diabetes, Black Africans might adhere to diabetes self-management advice compared to another ethnic group, because of their perception of the severity of their diabetes and related complications. For example, people who have their treatment regimens changed because of the severity of diabetes or risk of complications. In contrast, Lawton et al. (2007) argued that South Asian people often blame external factors such as migration experience to western countries, as the cause of diabetes perception and behaviour. This simply explains that visible experiences could affect an individual's lifestyle choices and

concepts of their relationship to their illness. On the other hand, Macaden and Clarke (2006) highlighted that disease sensitivity and perception could be influenced more by people's lack of understanding and knowledge of the severity of the disease, especially among older people.

Moreover, people's behaviour towards health and illness could be influenced because of fatalistic beliefs whereby people feel unconcern as the disease is a common illness (Mosnier-Pudar et al., 2010; Patel et al., 2015). This could be because of family history of the disease, genetic history, age, community history and religious belief (Lawton et al., 2006; Mosnier-Pudar et al., 2010; Johnson et al., 2011; Lucas et al., 2013). Fatalistic view of diabetes occurrences has been associated with cultural beliefs and religious beliefs among minority ethnic groups, and this has been reported in different studies. Although a family history of diabetes and relatives' experiences was reported for diabetes occurrences in some studies (Greenhalgh et al., 1998), other studies reported that diabetes and other health conditions attributed to the will of God (Farooqi et al., 2000; Darr et al., 2008; Lucas et al., 2013). Hence, individuals are not regarded as being responsible solely for their health and illness. So the illness is viewed as being inevitable. On the other hand, Ludwig et al. (2011) study reported that women showed more sense of fate concerning health risk and weight gain attributing it to ageing. It was evident from the DAWN study that people's fears and anxieties about diabetes-related complications, despite the absence of any form of complications, could be triggered by early diagnosis, previous experiences, other people's description of their illnesses or knowledge about potential complications (Funnell, 2006). This shows that previous information about diagnosis and illness could subject individuals to a sense of fate. Similarly, Mosnier-Pudar et al. (2008) identified the denial of noncompliance as another health-related behaviour that could influence diabetes self-management. The APPGD (2015)

report identified the gap in knowledge about the seriousness and severity of diabetes, resulting in people not feeling the need or necessity to develop skills to manage their diabetes better. The knowledge about the psychological toll of managing diabetes as a long-term health condition could result in people disengaging from recommended regimens (APPGD, 2015).

Moreover, other studies observed that the relationship between knowledge, treatment and health outcome for health service users are inconsistent over the years, despite health interventions (Abubakari et al., 2013; APPGD, 2015). People can still engage in unhealthy behaviour and lifestyle despite knowledge about risks to health, giving rise to poor self-management. This could be because of a misunderstanding about diabetes and its treatment and limited awareness of health information and health education. APPGD (2015) reported from their study, that when most diabetes education is signposted and delivered, people with diabetes are often given little information and explanation about the aims and benefits of participating in the programme. As a result, many people doubt the usefulness and relevance of the recommended programmes. To support this notion, Carr (2012) argues that insufficient knowledge about diabetes management could still affect people's ability to adopt healthy lifestyles, and likewise the diabetes information provided by HCPs. People might not understand the details about the nature of diabetes and the role that a healthy diet plays in its management. Therefore, there is the need for people to be made aware and educated about their nutrition, diabetes, treatment and how it can be appropriately managed and controlled (Connor et al., 2004). Carr (2012) further argues that people need to understand both their health condition and what actions are recommended, to be able to manage a long-term condition effectively. Therefore, people with diabetes need to understand how their diet, activities and medication interact to be able to maintain blood sugar level; know how to test

and monitor sugar level and how to adjust them (Carr, 2012). The National Service Framework and NICE guidance have also made it clear the importance of structured health education, including dietary advice, to aid self-management of diabetes (DH, 2001; NICE, 2011b). NICE states that “*individualised and ongoing nutritional advice from a healthcare professional with specific expertise and competencies in nutrition*” should be made available for people with diabetes (NICE, 2015b). Furthermore, structured and nutrition educational advice provided by HCPs should support self-management attitudes, beliefs and knowledge of diabetes patients (NICE, 2015b). However, Newman et al. (2004) argued that health and disease knowledge might not be enough to promote and support effective management approaches, other moderating factors, which could be an individual, social or environmental, and the effects of intervention and management needed to be considered to improve range of diabetes outcome. Similarly, Airhihenbuwa et al. (2007) advocate the need for further research on culturally appropriate health intervention to help reduce health inequality among Black African populations in the UK. Therefore, it is important to consider how individuals’ health is understood and interpreted in a socio-cultural context.

2.6.2. Cultural food and diet preferences

Diet is an essential component of diabetes care, yet full adherence with the dietary course of therapy advice and routine by people with T2D often proves challenging to accomplish due to people’s traditional beliefs, lifestyle and comfort eating (Lawton et al., 2008; Withall et al., 2009). Several studies have reported that older people of African descent do favour certain dietary habits and traditional diet despite the risk of a related nutritional condition such as obesity and diabetes (Brown et al., 2007; Harrison, 2014). Sometimes foods, such as rice and meat are not recommended for diabetes control but have cultural significance and identity to specific ethnic groups (Lawton et al., 2008). The dietary habit and pattern of cooking, which

is different from western eating habits were related to individual cultural practices and health beliefs (Harrison, 2014). People tend to find traditional food to be more available accessible locally. Other studies discussed how African and some other Asian countries found it difficult to adhere to dietary advice because traditional diet and pattern is not included in management regimens (Khanam and Costarelli, 2008; Johnson et al., 2011).

Nonetheless, other studies identified that food and dietary preference could positively influence people's self-management for diabetes. Chlebowy et al. (2010) found that internal factors which are self-related, such as lack of self-control over nutritional habits impact on self-management behaviours. According to Withall et al. (2009) study on people's perception of influence on diet, many people tend to prioritise traditional food and family preference over health choices. Others may be due to the cost of buying healthy food advised by HCPs (Withall et al., 2009). In addition, Everson-Hock et al. (2013), Grace et al. (2008) and Wood et al. (2010), argued that lack of precise information, misunderstanding of food and diet messages and complexity of healthy eating messages from HCPs could also be a barrier to behavioural diet change for people with T2D. This is especially so with the classification of fats and sugar content in food, cutting out specific foodstuff instead of restraining from risky foodstuff, and the 5-a-day messages misinterpreted as five portions of fruits. On the other hand, Schulze and Hu (2005) systematic review of prospective cohort studies and randomised clinical trials for primary prevention of diabetes emphasised on the impact of the western diet. They reported that a typical Western dietary pattern, rich in red and processed meats, refined grains, sugar-sweetened beverages and desserts was associated with an increased risk of T2D.

Nevertheless, Lewton et al. (2008) argued that although diet and lifestyle are observed as an important intervention factor for diabetes prevention and management, full support with dietary advice given by HCPs to people with T2D can often be difficult to achieve due to the limitation to individual and traditional food preferences. Although people from the BsSA communities can face a problem with diabetes advice because of food beliefs and eating preferences (Connor et al., 2004) that current dietary information may not address, the dietary advice provided for the population tend to be based typically on British diet (Scott, 1997). On the other hand, Connor et al. (2004) and Carr (2012) studies reported that people with T2D from the BME group faces the problem of adherence to health-related dietary advice for diabetes management because of a certain culture, food beliefs and eating preferences that are not included in a typical British diet regimen. Carr (2012) further highlighted that some ethnic group could hold onto a food diet because of cultural beliefs related to religion and traditional medicine. Lawton et al. (2008) concluded that the health advice given to people with diabetes is limited because there is more focus on the European lifestyle and food. Thus, people are not properly informed and educated about what traditional food to eat and the ones to avoid.

On the other hand, Carr (2012) highlighted that lack of specificity on health and food advice could be from lack of detailed knowledge among HCPs about people's culture and beliefs in relation to disease management. Furthermore, Carr (2012) argues that most health advice given to people with diabetes did not consider the culture, health language and environmental factors which could influence health management; thereby limiting the relevance of health advice and treatment for minority ethnic groups in the UK. The evidence from Carr's study suggested the need for HCPs to tailor health-related dietary advice to suit individual needs, with more focus on the individual's eating habits, culture and religion. Similarly, Lawton et

al. (2008) suggested that recommendation should be made relevant to people's usual diet without compromising their taste for some food because food has a specific value and significance to different minority ethnic groups. In support of the notion above, NICE (2015b, p.15) stated that “*people with diabetes should be provided with dietary advice in a form sensitive to the individual's needs, culture and beliefs, being sensitive to their willingness to change and the effects on their quality of life*”. People's cultural beliefs about their general health may have an impact on disease management when self-management strategies advised, which include dietary restrictions, and physical activities are irrelevant and uncomfortable.

Furthermore, Mosnier-Pudar et al. (2010) argued that people's diet could influence diabetes management because of a lack of social or family support. When there is little or no motivation from friends and family to help control diet, people living with T2D may be depressed or discouraged with the struggle between diet restriction, health advice and overindulgence (Mosnier-Pudar et al., 2010). Besides, people can be affected by depression and anxiety because of stress from illness management (Schoenberg et al., 2009), functional limitations and cost of health care, which makes it difficult to adhere to dietary advice (Johnson et al., 2011). However, significant cultural factors and beliefs affecting nutritional knowledge among people from the Black African population living with diabetes are yet to be explored extensively.

2.6.3. Religious beliefs and spirituality

Religious beliefs and spirituality play a considerable role in the beliefs and practices of people from African origin (Casarez et al., 2010). Several studies demonstrated how religious beliefs and spirituality impact on diabetes behaviours (Stone et al., 2005; Lawton et al., 2005;

Brown et al., 2007; Grace et al., 2008; Darr et al., 2008; Lawton et al., 2008; Greenhalgh et al., 2011; Kohinor et al., 2011; Duke and Wigley, 2016). However, there are limited studies looking at how religious belief and spirituality play a significant role in self-management behaviour among BsSA communities, and how this can improve health outcomes. Moreover, recent studies on diabetes and illness beliefs are small exploratory studies primarily addressing spiritual beliefs impact the approaches to diabetes treatment plan, resulting in poor diabetes care. They are more focused on South Asian and Afro-Caribbean identified as more likely to adhere to structured religion; especially the Muslims. Thus, little is known about how spiritual beliefs and practices and social support affect self-management of diabetes among the BsSA communities. Therefore, identifying and supporting all likely motivators for self-management behaviours is essential for enhancing health outcomes in this vulnerable population.

Religious and spiritual beliefs and activities can help in coping with a chronic illness by providing support, confidence, and hope, or they can hinder successful management, as people may neglect self-management regimens by relying on prayer to manage their illness. Most commonly cited impacts of religious belief on diabetes outcomes are about the negativity on management behaviours (Lawton et al., 2007; Stone et al., 2005). However, the work of Polzer and Miles (2007) disputed this fact by reporting the evidence that spiritual beliefs improve disease management among African Americans with diabetes. Notably, religious beliefs and spirituality demonstrated significant positive outcomes with glycaemic control among Black women with T2D (Newlin et al., 2008). Several other studies have also highlighted the positive influence of religious beliefs and spirituality on diabetes behaviour, especially among the South Asian population. Spiritual beliefs were reported to be an essential source of emotional support for PLWD (Brown et al., 2007; Samuel-Hodge et al.,

2000; Stone et al., 2005). God is perceived as central to providing strength to deal with everyday challenges and controlling diabetes through a firm belief in God, prayer, meditation, and support from church members (Samuel-Hodge et al., 2000; Polzer and Miles, 2007). Prayer was believed to reduce stress, which has become a prominent belief among South Asians and Black African Americans as one of the leading factors that contribute to the onset of chronic diseases such as diabetes (Samuel-Hodge et al., 2000; Schoenberg et al., 2009). Similarly, religious beliefs were reported as fundamental over dietary advice (Samuel-Hodge et al., 2000; Wallin et al., 2010). Casarez et al. (2010) study found a similar comparison among Christian African Americans who showed that spirituality might reduce commitments towards self-management, diet regimens, exercise and taking medications to improve diabetes outcomes. Although there was a report about the genetic history of diabetes, Darr et al. (2008) establish that religious beliefs gave some level of free will and ownership of health to some individuals. Nonetheless, some of these attitudes inevitably lead to reduced motivation and confidence to effectively self-manage chronic diseases. Darr et al. (2008) and Brown et al. (2007) further argued that responsibility for health lies within individual despite the fatalistic belief that health condition could be the will of God.

On the other hand, the relationship between an individual's knowledge and health outcomes was found to be inconsistent (Grace et al., 2008). While some people show positive fatalism, others were found to have a negative, fatalistic belief in their health. Nam et al. (2011) study stressed that culture has a strong influence on an individual's beliefs, knowledge, and behaviours, which in turn affected the management of their diabetes. Spirituality and religious-focused management were reported to be beneficial to African Americans with diabetes as they usually rely on God for support (Nam et al. 2011). Several studies found that most Muslims, and some Hindus and Sikh participants reported a significant control over

their health and ordered the events in their life (Greenhalgh et al., 1998; Chowdhury et al., 2000; Stone et al., 2005; Lawton et al., 2007; Greenhalgh et al., 2011). For example, Muslim participants reported that having diabetes was the will of Allah, beyond their control and as such resign to fate (Greenhalgh et al., 2011). Most participants were generally concerned about the impact of poor diabetes control and reacted with shock and denial at the perceived consequences of diabetes complications. Some Muslim participants had perceived an attitude of ‘enjoying life and leaving the rest to Allah’ or citing family history or a view that it was God’s will (Lawton et al., 2007; Stone et al., 2005).

Given that little is known about how spiritual and religious beliefs play a role in self-managing of diabetes among people from the BsSA communities in the UK, this study examined the relationship between spirituality, religion, and diabetes self-management activities in this population.

2.6.4. Stigma and discrimination

It has been reported that public awareness and knowledge about diabetes influence the way the disease is perceived at both individual and community levels of understanding health and illness (APPGD, 2015). This can have an impact on diabetes care delivery and health outcomes (Diabetes UK, 2016). Some studies have reported that people from the African origin are sometimes affected by myths and misconceptions about diabetes and its treatments. They also have a fear of disclosing their illness due to the stigma attached to unhealthy behaviours (Brown et al., 2007; Noakes, 2010; Harrison, 2014). The APPGD (2015) report suggested that people, especially those from some Black, Asian and minority ethnic community might not take a necessary adjustment in lifestyle or adhere to medical treatment. They may also depend on alternative remedies exclusively because of the assumption of

discrimination directed towards persons for unhealthy lifestyle or behaviour when visiting HCPs. This Stigma is a poorly informed stereotype that everyone with T2D is personally responsible for bringing the health condition on themselves (Huber, 2014). Similarly, Wagner et al. (2014) and Potter et al. (2015) argued that weight stigma and discrimination of people with T2D prevents the delivery of equitable and efficient medical care, and discourages people from seeking diagnosis and treatment because of diabetes-related guilt, self-blame and depression (Mosnier-Pudar et al., 2010), which can result in poor diabetes outcomes. Also, Winkley et al. (2015) study identified shame and stigma of the illness as an important reason for non-adherence to diabetes education

These studies demonstrated the importance of understanding that diabetes is associated with health-related stigma, which may affect the satisfactory performance of daily acts of self-management and individual's participation in health advice and programmes, resulting in poor health outcomes.

2.6.5. The role of family and social support

Current trends in diabetes treatment and management place huge importance on individual responsibility and empowerment to manage own illness and health condition; requiring a certain level of family and social support. T2D is a long-term condition that requires a lifelong commitment, which necessitates changes in behaviour and lifestyle pattern. Therefore, families and social support for people with T2D are necessary and essential aspects of diabetes management behaviour (Lagreca et al., 1995; Gallant, 2003; Diabetes, 2009b; Wearden and Bundy, 2010). The information and support received from families and friends, including functional or emotional support, financial support, health education, healthy eating advice, self-management services and trust play vital roles in the outcome of

their diabetes self-management behaviours (Schiotz et al., 2012; Mensing et al., 2007; Diabetes UK, 2009b).

Several studies have assessed the influence of social and family support on diabetes management behaviours. Good level of family and social support in diabetes-related health behaviour has been demonstrated in some studies, showing affirmative compliance with treatment regimens, positive changes to diabetes self-management behaviour and good quality of life (Gao et al., 2013). Stopford et al. (2013) review of the association between social support and glycaemic control reported a beneficial effect of social support on glycaemic control. Brown et al. (2007) and Mayberry et al. (2014) argue that families and social support could affect diabetes management behaviour and diabetes care outcome among Black African populations in term of family belief, culture and experiences of illness. Similarly, Wearden and Bundy (2010) argued that though families and friends may provide emotional support, they could also undermine individuals with diabetes attempts at self-management through criticism.

The influence of social and family support on diabetes management behaviour among Black African populations have also been stated in other countries, for example, America, Canada, Norway and Nigeria (Chlebowy and Garvin, 2006; Tang et al., 2008; Jones et al., 2008; Adejoh, 2012; Miller and DiMatteo, 2013; Mayberry et al., 2014). Jones et al. (2008) study on the impact of family and friend on management behaviour of people with diabetes found that families and friends made a significant difference in individual's diabetes management behaviour and participation in a culturally tailored group programme. Similarly, Miller and DiMatteo (2013) argued that family and social support are significant aspect health intervention that promotes adherence to diabetes management and health care. In addition,

Oftedal (2014) reported that participants perceived practical support from families and friends, in terms of diet and exercise, to be helpful and valuable, though lack emotional support appears to demotivate some other participants' diabetes management. However, Adejoh (2012) study of diabetes management behaviour of the Igala ethnic group in Northern Nigeria reported that some of the family support provided to people with diabetes, even though were well-intentioned, had unintended negative consequences or influences resulting in negative diabetes management behaviour and outcomes. For example, people suggesting food for eating or other treatments outside the recommended food and treatment from the hospital (Adejoh, 2012). Similarly, Jones et al. (2008) reported that though families and friend may sometimes be helpful sometimes in individual's diabetes management, they could also create an environment that makes good diabetes care and management unachievable for people with diabetes. Nevertheless, Chlebowy and Garvin (2006) and Tang et al. (2008) suggested from their study that coherent beliefs from families could improve individual's self-care behaviour and health-related outcomes. Thus, leading to fewer depressive symptoms and improved the diabetes-specific quality of life and better adherence to diabetes regimens. Similarly, Mayberry et al. (2014) suggested based on a focus group study to explore the role of family support in adults, that reduction in obstructive family behaviour can improve the self-efficacy of self-care of people with diabetes.

The impacts of social and family support as a barrier to positive lifestyle changes have also been reported in other ethnic groups in the UK. Findings from Grace et al. (2008) suggest that the complex value hierarchy of social norms of hospitality among British Bangladesh population in the UK explains the disagreement with certain health recommendations. Grace et al. (2008) further highlight the role of moral conflicts between individualist goals of healthy eating and collectivist goals of providing and partaking in "*special menu*"

occasionally with the family guest to avoid shame or lack of hospitality, which families might find offensive. Nevertheless, Grace et al. (2008) study identified the importance of family and social support with an emphasis on improving self-management behaviour and adherence to dietary regimens. In summary, family and social support have been shown to have some effect and impact on diabetes-related management behaviour and health outcome.

2.6.6. Negotiation of roles of HCPs in T2D self-management

Communication between health providers and service users is vital in diabetes self-management. This is more so because of the complexity of diabetes as a long-term illness and the individual's role in managing their health for improved health outcomes (Wilson et al., 2012).

2.6.6.1. Interaction with HCPs

The importance of patient-provider interaction has been noted in several studies identifying that positive contact with HCPs during and after diagnosis. The communication of the benefits and significance of self-management and the joint formulation of a manageable self-care plan helps to improve diabetes outcome and reduce diabetes-related complications (Polonsky et al., 2010; Bundesmann and Kaplowitz, 2011). Verhoef et al. (1999) and Johnson et al. (2006) reported that improved level of patient-HCP interaction increases patients' satisfaction on advice for a behavioural change, adherence to self-efficacy associated with better compliance with treatment regimens and improved patients' general well-being. Similarly, Bundesmann and Kaplowitz (2011) study found that medical information and health knowledge provided by HCPs to people with T2D had a positive influence on people's self-management behaviour and outcomes; including diabetes care, blood glucose

monitoring, exercise and participation in a routine screening. However, HCPs lacking the awareness of specific culture, needs, and expectations of people living with T2D among the BME communities create barriers to continued interaction (Chowbey et al., 2008; Bamonte et al., 2015).

The importance of communication between the service user and the service provider is to provide a better understanding of their role in self-managing their illness and helping them to cope with the disease during the process of lifestyle or behavioural change. Therefore, it is crucial that HCPs assist and educate their clients with adequate information that would provide realistic and achievable goals for behavioural change. They could encourage them by listening, explaining information and showing interest in their concerns and needs (Wilson et al., 2012; Johnson et al., 2006). Rubin et al. (2006) study found that positive patient-provider interaction had a significant impact on adherence to treatment and changes in diabetes self-management behaviours. Also, Kennedy et al. (2007b) argued that effective self-management of a chronic disease like diabetes requires fundamental changes in the way HCPs relate to individuals affected and how health care is being delivered equitably. Nonetheless, Wilkinson et al. (2014a) argued that the tension remains between people who want to be in control of their own health decisions, but also wanting their HCPs to oversee their health. Lack of communication of health needs and feelings to HCPs is therefore seen, as a barrier to self-management when professional could not attend to the unexpressed needs of the person with diabetes (Wilkinson et al., 2014a). Hence, joint interventions become relevant to improve patient-provider interaction and relationship and to reduce the barrier to effective management.

2.6.6.2. Inadequate health provider information

The information given by HCPs has also been recognised to influence people's diabetes behaviour (Nam et al., 2011; Shrivastava et al., 2013). HCP's knowledge, belief and attitude toward disease causation, which is based on medical discovery and knowledge, have an impact on diabetes management. When HCPs do not to have enough knowledge and therapeutic approach to treating and managing patients holistically, this affects the information provided to their patients (Nam et al., 2011). According to Zamanzedeh et al. (2015) study, providing holistic care increases the level of understanding of HCPs about their patients and their needs. Also, most of the health advice given by HCPs are medically and scientifically driven, which could be discomforting and unsatisfactory to the service users (Zamanzedeh et al., 2015). People with diabetes may feel helpless and anxious during diagnosis, so lack of appropriate interaction or communication with the HCPs could affect the management of their illness. In sociocultural context, Chinenye and Ogbera (2013) state that the scientific description of diabetes during diagnosis as chronic non-communicable diseases depicts the limitations of biomedical medicine and encourages people with diabetes who have cultural beliefs to turn to traditional healers or alternative medicine rather than modern medical treatment.

Several studies report participants' experiences with negative issues relating to accessing culturally sensitive information from HCPs (Stone et al., 2005; Lawton et al., 2006; Brown et al., 2006; Lawton et al., 2008; Greenhalgh et al., 2011; Kohinor et al., 2011). Lack of culturally sensitive facilities and gender-related issues were also reported as contributory factors for not accessing certain diabetes care services. Stone et al. (2005), Lawton et al. (2006) and Greenhalgh et al. (2011) studies found that some women avoided mixed-gender leisure facilities, diabetes education sessions and male HCPs due to social and cultural beliefs

about modesty. Moreover, Lawton et al. (2006) found that people from Pakistani and Indian origin with T2D believe the purpose of health care services is to make a quick diagnosis and treatment of diabetes-related complications, rather than the provision of advice about managing their diabetes. On the other hand, Brown et al. (2006), Lawton et al. (2008) and Kohinor et al. (2011) studies reported culturally insensitive advice or conflicting diet information from HCPs.

The APPGD (2015) report showed that most diabetes education programmes and support provided to people with diabetes only partially meet people's needs when adequate health information that suites person's preferences in terms of the design, content and delivery of education courses are not considered. APPGD (2015) further suggested a more holistic approach that incorporates, among other social and cultural needs, the emotional and mental well-being of people with diabetes, support for family and carers, and information about a new diabetes care practice that people use to manage their health. Different learning styles are therefore required to be considered to ensure that adequate information and skills training reaches as many people as possible (APPGD 2015).

2.6.6.3. Low compliance with professional medical advice

Several studies have reported that people did not follow expert opinion due to a lack of cultural knowledge, religious and language differences, or other contextual factors, which were sometimes miss-interpreted by HCPs (Chowdhury et al., 2000; Lawton et al., 2005; Lawton et al., 2008; Stone et al., 2005; Fleming et al., 2008; Kohinor et al., 2011; Greenhalgh et al., 2011). Participants of some the studies expressed the importance of the traditional norms and beliefs about their foods to be incorporated into dietary recommendations (Lawton et al., 2008; Fleming et al., 2008). Chowdhury et al. (2000) reported that individuals from

BME groups consume foods that are high fat and sodium content and many of the participants in the study express difficulty in giving up traditional foods and certain lifestyle related to cultural tradition. These factors have emerged to contribute to their non-adherence to the professional recommended diet plan. Similarly, Kohinor et al. (2011) study reported conflicting professional dietary advice and prescriptions that were contrary to participants' traditions.

On the other hand, Lawton et al., (2005) and Fleming et al. (2008) study reported that participants deliberately reduce the use of prescribed medication without medical advice from their doctor and only use them when they feel unwell despite awareness of the importance of prescribed medication for their diabetes. In another study, the stigma associated with having T2D was reported as a major factor contributing to low compliance with professional medical advice (Lawton et al., 2007; Greenhalgh et al., 2011). Macaden and Clarke (2010) argued that medical models of diabetes management relied on individual compliance, leading to poor diabetic control and outcomes. Besides, the biomedical perspectives of compliance often perceive individuals who refuse to comply with treatment regimens as exhibiting non-compliant behaviour, failing to recognise the individual's voice in making decisions about their condition (Keszthelyi and Blasszauer, 2009). Consequently, it is essential to explore the cultural boundaries created by individuals on illness and management behaviours.

Brown et al.'s (2007) study reported that the beliefs of people from a Black African origin, about diabetes, tend to be consistent with an individual's cultural or personal values. The cultural values consequently shape their decision on diabetes management and acceptance of medical advice. Similarly, Lucas et al. (2013) study among the UK South Asian population revealed that individual's social and cultural norms affect the acceptability of the intervention

and delivery of lifestyle advice by HCPs. Sociocultural influences and differences can be seen in people's traditional ways and patterns of food consumption, cooking, symbolising generosity and belief in a culture (Nettleton, 2013). For example, in Africa, meat and wine consumption are associated with people's level of wealth and respect, while consumption of fruits and vegetables are classified as a form of dessert and supplements. Also, others do take fruits and vegetable for medicinal purposes with the belief that fruits help digestion after eating.

Brown et al. (2007) and Carr (2012) looked at the perception and ways African people with diabetes manage their illness and respond to dietary advice, whereas Harrison (2014) explored diabetes belief system that drove the lifestyle and behaviour of people with T2D, augmenting the development of future initiatives. Harrison (2014) reported that ethnic differences coupled with specific sociocultural factors contribute to more adverse outcomes of diabetes care. Harrison (2014) concluded that knowledge of ethnic beliefs is important for HCPs to ensure effective management of diabetes among ethnic minority population in the UK.

2.6.7. Use of alternative remedies for care and treatment of T2D

Previous studies have shown that multiple health-seeking behaviours may account for the use of other health remedies for diabetes treatment and management (Scott 1998; Manya et al., 2012; Patel et al., 2015). The use of alternative remedies, such as home remedies, food remedies, and complementary and alternative medicine, has been identified as a common means of managing diabetes. Non-western and non-medical practitioners remain a favourite alternative source of diabetes care in the minority ethnic population (Harrison, 2014). Harrison (2014) found that people with T2D use different practices and procedures for

diabetes treatment and management, including self-treatment with herbs, traditional healers, complementary and alternative medicine. Harrison (2014) and Chinenye and Ogbera's (2013) study, reported that non-biomedical remedies and alternative medicine were used independently due to their trust and belief in individual cultural norms and their significance. According to Harrison (2014), different dynamics of cultural beliefs and practices influence people's actions in the non-acceptance of biomedical regimens in favour of self-care, home remedies and consultation with non-medical practitioners. On the other hand, Winkelman (2009) argued that people tend to use other remedies for diabetes care because of availability, affordability and cultural familiarity. There is the belief that certain traditional herbs like bush tea and Aloe Vera can cure diabetes. Arora et al. (2009) study found that the consumption of Aloe Vera juice by 28 study participants diagnosed with T2D over a 3 month period resulted in the significant reduction of HbA1c, glucose and lipid levels as well as BMI. Therefore, people see some of the plants more accessible and sometimes use it interchangeably to complement prescribed medications (Moss and McDowell, 2005; Nichter, 2008).

There is evidence that people do choose an alternative or complementary remedies above medical treatments in a variety of contexts, which have a potentially profound impact on health behaviours (Brown et al., 2007; Harrison, 2014; Patel et al., 2015). Brown et al. (2007) study found that there was a preference for herbal remedies among participants of the study because of mistrust of toxicity and chemical composition of the doctor's prescribed tablets for managing diabetes. Similarly, Patel et al. (2015) study reported that treatment control beliefs on the use of alternative medicine were associated with better health status. Participants from the study highlighted the use of alternative remedies to improve diabetes control and reduce glucose levels to complement allopathic medication prescribed by a clinic. There were preferences for natural ingredients and food remedies, as these were believed to

be less harmful to the body. They also believed that they would be cured, based on the report from other people within the community using the remedies (Patel et al., 2015). Patel et al. (2015) findings showed that the sociocultural context of the population shaped illness beliefs and self-management behaviour. Patel et al. (2015) study among the South Asian community, further suggested that although individual's fatalistic attitudes and beliefs influence self-management behaviours and practices, people tend to seek alternative treatments, including food therapies often recommended by social networks and friends or families. People often assume they have well informed and accurate information through their social networks. The use of herbal remedies or traditional medicines remain more important and very popular for certain ethnic minority groups; based on their general belief in its perceived effectiveness and other preferences compared to the usage of western medicine (Pieroni et al., 2008; Harrison, 2014). Nonetheless, people from Black African origin often use alternative remedies as supplementary medication rather than as a complete alternative to western medicines. Therefore, it could be said that factors such as cultural beliefs constrain the behaviour of people with T2D and play a culturally significant role in an individual's decision to seek treatment and management advice outside medical care, and where to seek it (Nam et al., 2011).

The use of traditional medicines, CAM, and herbal medicines in conjunction with medical treatments for diabetes self-management have also been widely reported in many countries in Africa , including Ghana, Kenya, Cameroon, Nigeria and Tanzania (Ogbera et al., 2010; Aikins, 2005; Awah, 2006; Awah, Unwin, and Phillimore, 2008; Kolling et al., 2010; Keter and Mutiso, 2012). This system of treatment is often referred to as medical pluralism, which is the presence of more than one therapeutic system. There is evidence to suggest that the use of alternative remedies in T2D management is prevalent among people from Africa descents

(Ogbera et al., 2010; Keter and Mutiso, 2012; Moshi et al., 2012; Semanya et al., 2012). When examining diabetes care among people from the African origin, it is imperative to consider how the use of other alternative remedies such as traditional medicines, herbal medicine, and CAM play a role in self-management behaviours. For example, Ogbera et al., (2010) study reported the use of complementary and alternative medicine among 46% of people with diabetes who participated in the study in Nigeria.

Despite the ongoing studies and evidence on the use of traditional and other alternative remedies in the treatment and management of T2D and the profound impact on health behaviour and outcomes, the recommendation has also been made to bridge the gap between conventional and unconventional medicine. This could further enable individuals' cultural and belief preferences to be incorporated in a more responsive and holistic health care system. Moreover, Bains and Egede (2011) study demonstrated that the insufficiency in the knowledge of T2D within a cultural context and how it affects self-management behaviours. Ignoring the influence of cultural beliefs on treatment-seeking behaviours contributes to major gaps presented in the studies on the prevalence of T2D among the BsSA communities. This knowledge is evident from Hoffmeister et al.'s (2005) study advocating the need to incorporate traditional Tanzanian diet into diabetes treatment and management regimens for Tanzanians, which would then reduce the conventional and biomedical way of approaching diabetes intervention in the country. The extensiveness of the use of CAM and traditional medicine among people of African origin is sufficient to suggest that Africans' traditional views about diabetes management differ from the biomedical model. There are differences in the way HCPs medically understand T2D and Africans culturally understand the disease. Therefore, assessment of peoples' cultural knowledge of T2D is essential in improving health and treatment-seeking behaviours.

2.6.8. Inadequate exercise and physical activity

Adequate exercise and physical activities have been identified as a specific measure necessary for diabetes management in the long-term. However, certain people are arguably less likely to be or remain physically active after diagnosis. A survey by Lawton et al. (2006), and Sriskantharajah and Kai (2007) showed a lower rate of exercise and other physical activities among British South Asians compared to other minority ethnic groups in the UK. Lawton et al. (2000) study on the level of physical activity among South Asians showed that people are sometimes aware of the importance of physical activity to diabetes management but do not exercise as expected. Participants from the study reported that social expectation and family support, time constraints, cultural norms and other health problems as the reasons for not fully participating in physical activities (Lawton et al., 2006). Some of the participants discussed the importance of cultural beliefs in choices for leisure time, which consequently influences engagement in local or community activities such as joining a sports team or using local leisure facilities (Lawton et al., 2006). Moreover, physical activities among Africans sometimes have a different purpose and social meaning (Johnson et al., 2011). For example, everyday activity such as housework, social gathering or events where people can participate in dancing, swimming and walking was a regular norm among African population and are mostly seen as ways of staying physically active. In addition, energetic exercise is unnecessary and unacceptable among certain culture, age and gender (Khanam and Costarelli, 2008; Johnson et al., 2011), which could also be related to religious or cultural obligations for modesty. On the other hand, Sriskantharajah and Kai (2007) reported that participants emphasised more on the importance of the day-to-day activities rather than the western concepts of organised exercise to losing weight or keeping fit. However, Khanam and Costarelli (2008) study reported that about 96% of the people that participated in the study stated that they would only take up advice for exercise or any other physical activity

based on their GP's referral as an alternative measure for treatment and management of their illness. This may be similar to people of Black African origin in the UK. Therefore, there is a need for further study to identify other sociocultural factors that prevent people from BsSA communities from engaging in regular exercise and physical activities.

Although several studies have explored the lay health beliefs and attitude about diabetes self-care behaviour among Black Minority ethnic population (Brown et al., 2007; Carr, 2012; Harrison, 2014), there are still limited studies to identify other cultural factors that influence self-management behaviour among the Black African population.

2.7. Living with Type 2 Diabetes

2.7.1. The management of T2D

To provide comprehensive care, diabetes self-management requires individuals with chronic illnesses to carry out day-to-day activities, alongside help offered by HCPs. It means having a more traditional model of care to promote health, decrease the risk of complications of illness and restore well-being (Lorig and Holman, 2003; Rijken et al., 2008; Hinder and Greenhalgh, 2012). The person with T2D plays a vital role in this process of self-management. Individual's daily routine of self-management of diabetes can be quite challenging, as it requires multiple management skills, including medical intervention, physical and emotional support, intellectual skills and training to manage the different needs of their condition (Diabetes UK, 2009b). Besides, self-management requires a high level of literacy and knowledge, modification of self-beliefs, behaviour, lifestyles or support through specific problem-solving and decision-making skills for self-monitoring, planning and engaging (Diabetes UK, 2009b; Abubakari et al., 2013). However, the demands of self-management

can be influenced by social, economic, cultural, psychological and environmental experiences, in terms of health resources, health information and personal circumstances (Hinder and Greenhalgh, 2012, Abubakari et al., 2013). The significance of self-management efforts and engagement strongly influence people's capacity and willingness to continue with the practice (Hinder and Greenhalgh 2012). The recommended behaviours for self-management includes exercise, dietary habits, medication, attending the routine screening, health education and health monitoring (Hewitt et al., 2010).

Nonetheless, Nettleton (2013) argued that the experiences of health or ill health and the skills required for management could only be understood entirely when either the sufferers or other lay people either affected by the illness and the service providers place importance on the meaning and interpretation of illness and healthy living. These activities can further be modified or reformed by other socioeconomic and behavioural factors associated with people's lifestyle and experiences (Nettleton, 2013). Similarly, Greenhalgh (2009), Wong et al. (2008) and Kendall et al. (2011) identified that apart from the biomedical task of managing illness, promoting and restoring health in self-management, it also entails personal characteristics, cultural, social and political dimensions of how people make sense of their health and illness. Osborn et al. (2010) and Wilson et al. (2012) emphasised that considering other factors that contribute to health help to optimise the educational intervention needed for people with T2D. On the other hand, Chlebowy et al. (2013) argued that T2D self-management, despite the importance, people often strive to adhere to the prescribed regimens such as dietary pattern, physical activity, self-administering oral medications or insulin, blood glucose monitoring and managing daily stress.

2.7.2. Diabetes self-management support and programmes outcomes in the UK

Several studies have identified the importance of diabetes education and intervention programmes offered to enhance diabetes knowledge and improved self-management abilities for the individual. These focus on the effectiveness of its performances and outcomes, particularly diabetes education (Skinner et al., 2006; Ockleford et al., 2008; Davies et al., 2008, Heller, 2009; Gillett et al., 2010; NICE, 2015b).

Self-management (SM) programmes are interventions structurally designed to improve the way individuals self-manage illnesses, optimise their health and well-being (NICE, 2011a). They educate people to properly self-manage their diabetes. In the UK, several formal and informal self-management programmes are offered by medical practitioners and health education specialists to people with diabetes, alongside with medical advice depending on the specific aspect of the diabetes care and needs. The intervention programmes include disease management, diabetes knowledge, insulin administration and adjustment, blood glucose control testing, diet and lifestyle changes and routine screening (Skinner et al., 2006; Deakin et al., 2006; NICE, 2011a; Diabetes UK, 2015). Besides, the programmes are tailored to specific population groups based on health behaviours and outcomes (NICE, 2011a). Nevertheless, non-adherence constitutes a major challenge despite the evidence supporting the benefits of the outcome of diabetes self-management education programmes (Gucciardi et al., 2009; Schafer et al., 2013). Nam et al. (2011) argued that some individuals may not accept self-management education due to disparities in accessibility and uneven provision to people with diabetes by different HCPs and HCPs. Similarly, Polonsky et al. (2010) argued that individuals might not be willing to attend self-management education programmes and manage their health better, especially when diabetes-related distress is high and motivation to participate is low, though may require education subsequently through support. Gillibrand

(2010a) stated that further study is required to explore the motivation and behaviour of people with T2D to health education.

The major focus of self-management policy for T2D education in the UK has been the Diabetes Expert Programme (X-PERT), Diabetes Education, and Self-Management for Ongoing and Newly Diagnosed (DESMOND) (Deakin 2006; Davies et al., 2008). Other educational programmes include DAFNE (Dose Adjustment for Normal Eating) for managing Type 1 diabetes and DEAL (Diabetes Education and Awareness for Life) for type 2 patients (DH, 2005). The diabetes programmes are aimed at ensuring people at risk of or diagnosed with; diabetes has access to the excellent quality structured programme, increase self-care independence, reduce the use of health services and achieve a successful health-related outcome (Donaldson, 2003; Deakin et al., 2006).

Nevertheless, education on diabetes assessment and self-management is neither consistent between community practices nor tertiary level centres (Wilkinson et al., 2014b). Wilkinson et al. (2014b) study reported that the sessions are rarely scheduled to satisfy individual's knowledge and family health information needs (Wilkinson et al., 2014b). A number of studies were conducted to evaluate the effectiveness of the diabetes programmes. A recent study from Deakin (2011) assessed the efficacy and delivery performances of X-PERT programme and reported that the programme was clinically effective and cost-effective for delivery on diabetes management. Other diabetes-specific structured programmes such as DAFNE and DESMOND have also been reported to have led to a modest but significant improvement in disease outcomes and health intervention in the UK health system for both service users and service providers; Diabetes UK and the Department of Health in the UK (; Skinner et al., 2006; Ockleford et al., 2008; Davies et al., 2008; Heller, 2009; Gillett et al.,

2010). Similarly, cost-effectiveness analysis of Gillett et al. (2010) showed that DESMOND intervention is likely to be cost-effective compared to the traditional care for people with T2D. Similarly, Skinner et al. (2006) three-month follow-up report indicated that DESMOND programme for newly diagnosed individuals changed health beliefs, metabolic control and quality of life of people with T2D.

Although some researchers have found that diabetes education programmes are effective with health improvement and lifestyle (Deakin et al., 2006), other recent studies have reported a less effective and a diminishing effect of the educational programme (Wadher, 2010, Khunti et al., 2012; Winkley et al., 2015). There was no strong evidence to indicate that self-management behaviour was effective in reducing mortality or morbidity rate in people with diabetes undertaking the regime of self-management over an extended period. Khunti et al. (2012) study to examine whether the benefits of the self-management structured programmes could be sustained for three years, reported that though there was continued improvement in some illness belief, the programme showed no major difference in biomedical or lifestyle outcomes at three years. Nonetheless, Khunti et al. (2012) suggested that an ongoing programme is required, as people may need continued education and support to manage their diabetes effectively. Old age, socioeconomic deprivation, low-income, ethnic minority and male gender have also been identified as reasons for non-attendance in diabetes programmes and less satisfactory health outcome (Eakin et al., 2002; Gulliford, 2007; Shah and Booth, 2009). On the other hand, Hinder and Greenhalgh (2012), and Roger et al. (2008) argued that there is a limited improvement in disease incidence, especially among the lower-socioeconomic group and ethnic minority population, despite people's efficiency in participating and completing the X-PERT Diabetes Programme and other health intervention programmes. Similarly, Taylor and Bury (2007) and Greenhalgh (2009) posited that

structured programmes focus primarily on relatively narrow biomedical or clinical information and techniques provided. They focus on health literacy and cultural norms, thereby making knowledge transfer difficult for people with low health education. Greenhalgh (2009) further argued that though the self-management programmes based on expert and the clinical model remains the preferred policy, the evidence base for their effectiveness also remains weak.

Other factors have emerged as a possible challenge for diabetes education programmes. Wilson et al. (2012) suggested that accessibility and provision of self-management education could be a major reason for the poorer effectiveness of the programme. While the education programme will be more accessible to some people and less accessible to others, the importance of self-management might similarly be unevenly promoted by people with diabetes and different HCPs and providers (Winkley et al., 2015). Winkley et al. (2015) study identified the shame and stigma of diabetes for a reason for non-attendance. This was reflected in how HCPs communicate health information to people with diabetes. Some other factors may influence an individual's decision on an intriguing possibility of participating in the education programme, including lack of motivation, lack of time, lack of knowledge on the importance of education and support (Ockleford et al., 2008). Ockleford et al. (2008) and Winkley et al. (2015) concluded diabetes self-management programmes could promote a long-term benefit if other individual factors can be considered when planning approach to diabetes intervention. Some other studies have also identified the importance of health literacy and motivation, good quality of patient-provider relationship and levels of social support and use of diabetes-specific education and how these can promote people's health beliefs, participation and health outcome (Szczepura, 2005; Ashtarian et al., 2012). On the other hand, Hastings and Chandler (2015) suggested an integrative and collaborative

intervention programme that allows HCPs to provide consistent information and practical skills to people with diabetes to be able to self-manage their diabetes. Therefore, diabetes self-management programme is an important step in promoting the diabetes knowledge and self-care activities for a better health outcome, provided there are positive interaction and collaboration with HCPs and individual management plan, initiating a positive, healthy behaviour, lifestyle and diabetes outcome (Polonsky et al., 2010).

It is evident from various studies that diabetes education is significant in promoting diabetes knowledge and improving diabetes-related behaviours associated with healthier self-management outcomes. However, it should be noted that individual's characteristics, including culture and health beliefs, might account for the inequality and limited access to health care, which may also have a subsequent influence on self-management behaviour and diabetes outcomes. Consideration of the wider picture of the health issues beyond the disease process is important in order to have an effective improvement in health outcomes within communities.

2.7.3. Necessity for holistic approach to diabetes self-management

The multifactorial complexity of T2D demands that all aspects its self-management and other major modifiable risk factors, such as obesity, diet and physical inactivities, require a proactive and complementary approach to prevent long-term complications and promote long-term health outcomes (Diabetes UK, 2009b; Ofori and Unachukwu, 2014). Various studies recognise diabetes as a complex chronic condition, whose management focuses on the prevention and control of diabetes-related complications, but less on the holistic approach in diabetes self-management (Wilkinson et al., 2014a; Wilkinson et al., 2014b). Wilkinson et al. (2014a) study recognises the importance of a comprehensive view of diabetes self-

management in terms of identifying diabetes treatment, and management beyond glycaemic control; a patient-centred approach to care and management, and long-term planning for diabetes as a continuing status. Similarly, WHO's 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Disease recommended a concerted approach that motivates individuals to adopt a healthy lifestyle (WHO, 2008). Moreover, Ofori and Unachukwu (2014) study reported that a holistic approach to self-management promotes positive health perception and support healthy behaviour.

The concepts of a holistic perspective in diabetes self-management is to promote individual's engagement and assist people with T2D to adopt a healthy behaviour or lifestyle and providing objective ways and skills to monitor outcomes (NHS Scotland, 2009; APPGD, 2105). It recognises the knowledge and understanding of individual's perspectives, and the impacts of sociocultural factors that typically limits the use of clinical resources in diabetes management and influences other diabetes self-management behaviour (Green and Tones, 2010). Sociocultural influences, including, family factors, peer relations, health beliefs and culture, not only influences the risk of developing T2D but also increase the collective risk of developing other diabetes-related complication and non-adherence to treatment and management regimens (APPGD, 2015). The notion of a holistic approach to self-management in this research illustrates how an inclusive approach to behavioural change enhances and support diabetes self-management behaviour in terms of prevention and control of diabetes-related complications.

2.8. Behavioural change theories

Health promotion is an essential aspect of health management intervention that explains health care beyond a simple understanding of disease prevention or treatment to empowering

and enabling individuals and populations to promote, improve behavioural change (Kickbusch and Payne, 2003; Baum, 2008; Green and Tones, 2010). According to Wearden and Bundy (2010), approaches to health intervention is individual-oriented. This approach is underpinned by a theoretical understanding of what motivates, regulates and maintains individual's health behaviour as a predominant influence on chronic illness like diabetes. It is concerned with the awareness of social determinants of health, the development, implementation and evaluation of health interventions that can affect individual's lifestyle and health outcomes and ensure effective self-management for behavioural change (Paskett et al., 2016). Therefore, these responses require the understanding of the individual's belief and perceptions through various behavioural theories that best explain and propose factors predicting health behaviour in a target population. It describes how sociocultural factors, such as individual health beliefs and cultural adaptation relate to self-management behaviours and explains how people make sense of and manage their illness (Harvey and Lawson, 2009). Several individuals, interpersonal and sociocultural factors are common among the behavioural theories that relate to an individual's perspective and experiences of diabetes self-management. These behavioural theories have been used to describe the influencing factors that influence individual willingness to embrace or disengage with any health intervention recommended for behavioural change. These models are; Health Belief Model (HBM); Health Promotion Model (HPM); Theory of Reasoned Action (TRA) or Theory of Planned Behaviour (TPB); Expectant Value Theory (EVT) and Social Cognitive Theory (SCT) (McQueen et al., 2007; Bandura, 2007). However, the most appropriate for this study is the Health Belief Theory and Social Cognition Theory underpinned by a modified sociocultural framework that could help guide the understanding of patterns of beliefs and behaviours related to diabetes self-management. It explains the various aspects of diabetes self-management, including the concepts of self-management; the views and experiences of

people with T2D and HCPs, with a focus on diabetes policy on self-management necessities, available intervention programmes and recommendations; and the influence of culture and health beliefs on diabetes self-management.

2.8.1. Health belief theory

The Health Belief Model (HBM) is a widely-applied health promotion and behavioural theory used to explain people's health behaviour towards treatment, prevention, management and adherence to prescribed medical regimens (Sheeran and Abraham, 1996; Wens et al., 2005; Nettleton, 2013; Clark and Janevic, 2014). Health belief model (HBM) was developed to explain and elucidate self-care activities, such as diabetes management recommendations with a focus on health-related behaviour in relation to prevention and management of the disease (Aalto and Uutela, 1997).

The Health Belief Model underlines the issue of interpersonal and sociocultural factors on individual conduct and actions towards health management and outcomes (Sheeran and Abraham, 1996). The HBM suggests that decision parameters including perceived susceptibility, perceived threat of disease, health effectiveness or values, perceived benefits, perceived barriers and cues of actions influence health behaviour and individuals' actions or level of motivation (Redding et al., 2000; Clark and Janevic, 2014). This model has simply been described as the readiness and willingness to change behaviour based on individual perception of susceptibility, severity, benefits and barriers (Strecher et al., 1997; Redding et al., 2000). According to Nettleton (2013), HBM can be used to identify the extent to which people are motivated to change their health-related behaviours or comply with health procedures based on individual's beliefs about health and illness.

Adejoh (2014) discussed in detail how the HBM variables could be used to explain adherence to a biomedical prescription for individuals with diabetes. The first variable describes how individuals will consider taking preventive actions to control and treat a certain issue and adhere to a medical prescription/regimen (insulin administration, blood glucose monitoring, diet, foot care and urine testing) if they perceive *they are at risk or susceptible* to the condition or other diabetes-related complications. The second variable describes the perceived *severity* of the health problem, ranging from perceiving complications, such as blindness and foot disease, to viewing diabetes as a life-threatening disease. The third variable describes when an individual perceives that the diabetes treatment and management regimens are *beneficial and more effective*, for example, eating regulated meals, taking regular exercise and monitoring sugar level will make an individual feel better and safer with engaging in the preventive behaviour and adhering to treatment regimens. The fourth variable, *barriers*, refers to how individuals understand the limited barrier and negative consequences of the action, for example, considering the cost of treatment over other responsibilities. The fifth variable, *cues to action*, describes how an individual receives a cue, which could be external (reminders from family members or friend to take medication and not to eat certain meals) or internal (stimuli triggering high or low blood sugar level) motivate individuals to perform healthy behaviours (Sheeran and Abraham, 1996; Adejoh, 2014). In addition to these variables, Bandura (2004) identified perceived self-efficacy as an additional variable to help explain further the conviction that individuals can successfully exercise control over their health and acceptance of care or services with the desire to achieve the desired outcome. This inclusion is further discussed in the next subsection and highlighted in Figure 2.3.

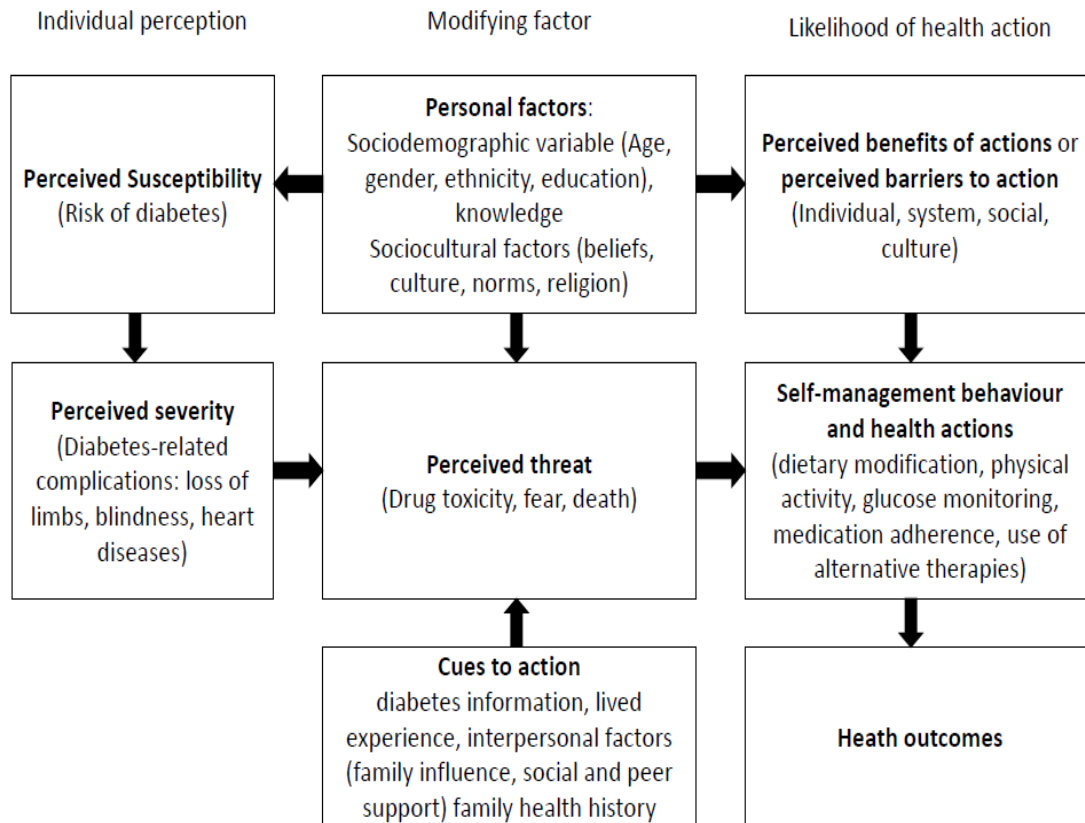


Figure 2.2. The health belief model (Adapted from Sheeran and Abraham, 1996)

Nevertheless, this model has been criticised for failing to consider cultural and other social factors that determine people's behaviour. Janz and Becker (1984) study found perceived barriers to self-care to be the most powerful dimension of the model to predict health behaviour and perceived severity to contribute to sick-role behaviour. Therefore, HBM was criticised for limited prediction of health behaviours based on attitude and cultural beliefs (Janz and Becker, 1984). Similarly, Carpenter (2010) study emphasised that perceived barriers and perceived benefits were consistently the strongest predictors of health behaviour, but that perceived severity was weakly predictive. In addition, perceived susceptibility was not found to be related to behaviour in the majority of studies (Harrison et al., 1992; Janz and Becker, 1984; Carpenter, 2010).

HBM investigates people's beliefs and perceptions, to identify the extent to which they are motivated to change their health behaviour (Nettleton, 2013). The HBM simply implies that people with T2D, for example, are more likely to change their behaviour towards health and illness, and accepted recommended support or intervention, if they feel threatened by their health condition or symptoms. Therefore, people with diabetes can adhere to a treatment and management plans if they feel they are susceptible to the health problem, worried about their health, perceived the serious consequences of the problem, perceived the benefits of accepting medical recommendation will reduce the threats and severity of the illness, and believe that the benefits of taking the action successfully outweigh the cost of not adhering to the action (Jalilian et al., 2014; McQueen et al., 2007).

Therefore, Health Belief Model is adequate to explain cultural practices and self-management behaviours in the prediction of health outcomes in sociocultural contexts. Belief in the efficacy of treatment regimens including diet, blood glucose monitoring and exercise play a significant role in determining self-management behaviours.

2.8.2. Social cognitive theory

According to Bandura (2004), Social Cognitive Theory explicates that while knowledge of health risks and benefits are essential for change, further self-influences and outcome expectation should be considered for change to occur. This is illustrated in figure 2.3. The Social Cognitive Theory (SCT) recognises the influence of other social factors as impediments and challenges to health situations that affect individual's responses to health behaviours (Bandura, 2004; Redding et al., 2000). The influencing factors could be physical, social, cultural, economic, political or situational depending on the individual perceptions and expectations (Redding et al., 2000). The theory emphasises the continuous dynamic

interaction between the individual, the environment, and behaviour (Baranoski et al., 1997). Furthermore, Bandura (2004) study identifies factors that can influence individual behaviour towards health, such as; knowledge of health risks; perceived self-efficacy, which is a personal belief in one's capability to exercise control over one's health behaviour; outcome expectations of health behaviour; setting health goals and experimenting specific action with the motive of attaining a desired action. However, Bandura (2004) argued that the health behaviour might be affected by the expected outcome, which may be the positive or negative effect on the behaviour. For example, people with T2D might adhere to diabetes self-management practice of managing their health condition because they feel empowered and have a sense of control of their overall health because of the individual responsibility feature of self-management.

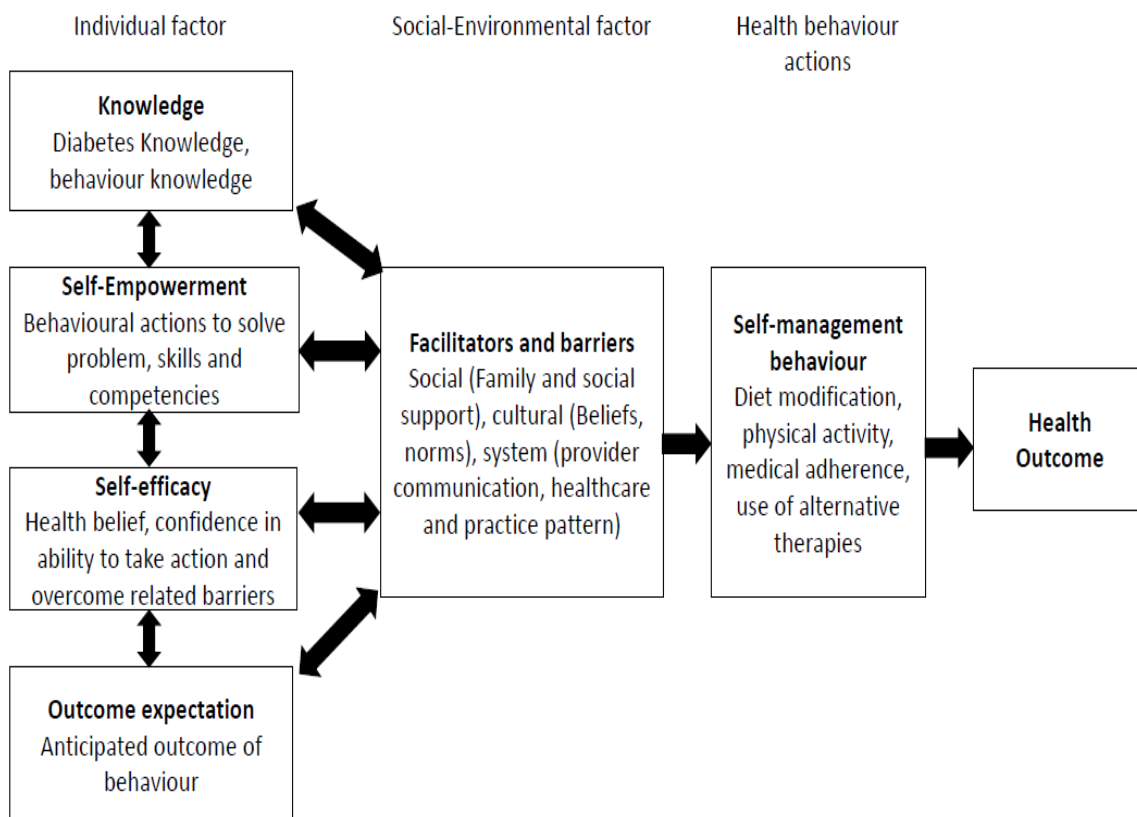


Figure 2.3. Social Cognitive theory (Adapted from Bandura, 2004)

Although this theory proposes that positive health behaviour is enacted if people perceived that they have control over the outcome and the capacity to execute the behaviour, there is still limited knowledge and studies on culture and beliefs as perceived facilitators and barriers for health management behaviours.

2.8.3. Conceptual model for the study – Socio-cultural model

Approaches to health-related behaviours have been considered to be individual-oriented, focusing on individual behaviour as the predominant influence on health outcomes. The proposed conceptual model used to synthesise the theories used in this research is drawn from a sociocultural perspective of Sanderson (2010) and a modified socioecological framework (MSF) for health promotion (McLeroy et al., 1988). According to Sanderson (2010), the sociocultural model emphasises the importance of understanding and use of culturally informed knowledge and experience of individual's behaviour and belief within a community to assess the use of medical treatment and services. It also looks at other health practices and the implications on self-management behaviours and health outcomes. Health outcomes are recognised as being shaped by wider determinants and modifying factors underpinning individual health choices and behaviour (WHO, 2008; Paskett et al. 2016). Therefore, this study considers the synergy of multiple factors such as; individual, interpersonal, social, policy and organizational factors that influence health outcomes (McLeroy et al., 1988). The model incorporates the role of culture and belief system more explicitly into understanding the disparities in health, illness and treatment as a multi-factorial pathway that defines a person or group interaction with the social-cultural environment and how that determines health outcomes (Marmot and Wilkinson, 2005; Foster, 2009; Sanderson, 2010).

Foster (2009) and Greenhalgh et al. (2015) described the sociocultural model as an anthropological perspective of health knowledge that helps in understanding the sociocultural nature of diabetes self-management and the cultural barriers that inhibit health behaviour. This model is identified as a behavioural framework that focuses on the individual's experience of health in social and cultural context, and the sociocultural factors related to health behaviour change, including an individual's attitude towards health, illness and healing (Uskul, 2010). The models underpinning this study describes how social and cultural factors inevitably influence health and determines person's experience, the definition of health and illness, access and adherence to healthcare, response to disease and complications, experience of healing, treatment expectation and health outcomes at different levels (Uskul, 2010).

The socio-cultural model conceptualises and elaborates on the previous assessed behavioural theories such as the Health Belief theory and Social Cognition Theory that are potentially modifiable within the context of sociocultural intervention for diabetes treatment and management (Adejoh, 2014). This model embraces the recognised predisposing, enabling, modifying and need factors at the individual level from the behavioural theories stated above (Figure 2.2 and Figure 2.3). It also consists of other health care system factors that can contribute to individuals' health outcomes. Social context, including life experiences, beliefs, social relationships, physical environment, society and community influences may function as either modifying condition or mediating mechanisms depending on the lived experiences between the intervention and health outcomes. As described above, sociocultural context shape socio-behavioural context, which also influences health behaviour and motivates health behaviour change, and individual experience of health and illness (Uskul, 2010; Nettleton, 2013). A similar argument for the role of sociocultural contextual influence can be made for the impact on non-adherence to biomedical treatment and noncompliance with management

regimens or self-management education programmes in favour of culture and home remedies (Uskul, 2010; Patel et al. 2015).

Exploring the culture and health beliefs within the context of diabetes self-management is important because it helps to view how people conceptualise diabetes self-management and their interpretation to intervention process and how this can shape health care practices, perception about illness and health intervention. This helps to describe people's health behaviour and disease perceptions, and how individual behaviours and habits influence health as well as explore the importance of cultural beliefs as a key component of health intervention. Understanding people's perceptions and beliefs about health, illness and self-care from a sociocultural perspective may provide a set of explicit and implicit guidelines that can shape their ideas about health and well-being, and improve their lifestyle (Uskul, 2010). Furthermore, it helps to acknowledge the cultural biases of patients, practitioners, and health officials in power and the role they play in a social and cultural system (Adejoh, 2014).

This theoretical foundation informs the study approach that places individual and community interest and experiences at the core definition of culturally sensitive health problem as well as the development of solutions at multiple levels designed to meet the needs and expectations of these communities (Foster, 2009). Addressing the need for a contextualised and culturally informed knowledge and experiences, a qualitative research informed by ethnography will be done with the people living with T2D to explore the specific cultural-bound knowledge and experiences with the self-management of T2D among Black African populations in the UK. This study will provide the in-depth knowledge about socio-cultural influences observed in various aspects of health and illness in diabetes management, drawing on the evidence from

health behaviour theories of health belief theory and social-cognitive theory of health promotion.

Consequently, the following conceptual framework presented in Figure 2.4. is drawn for this study

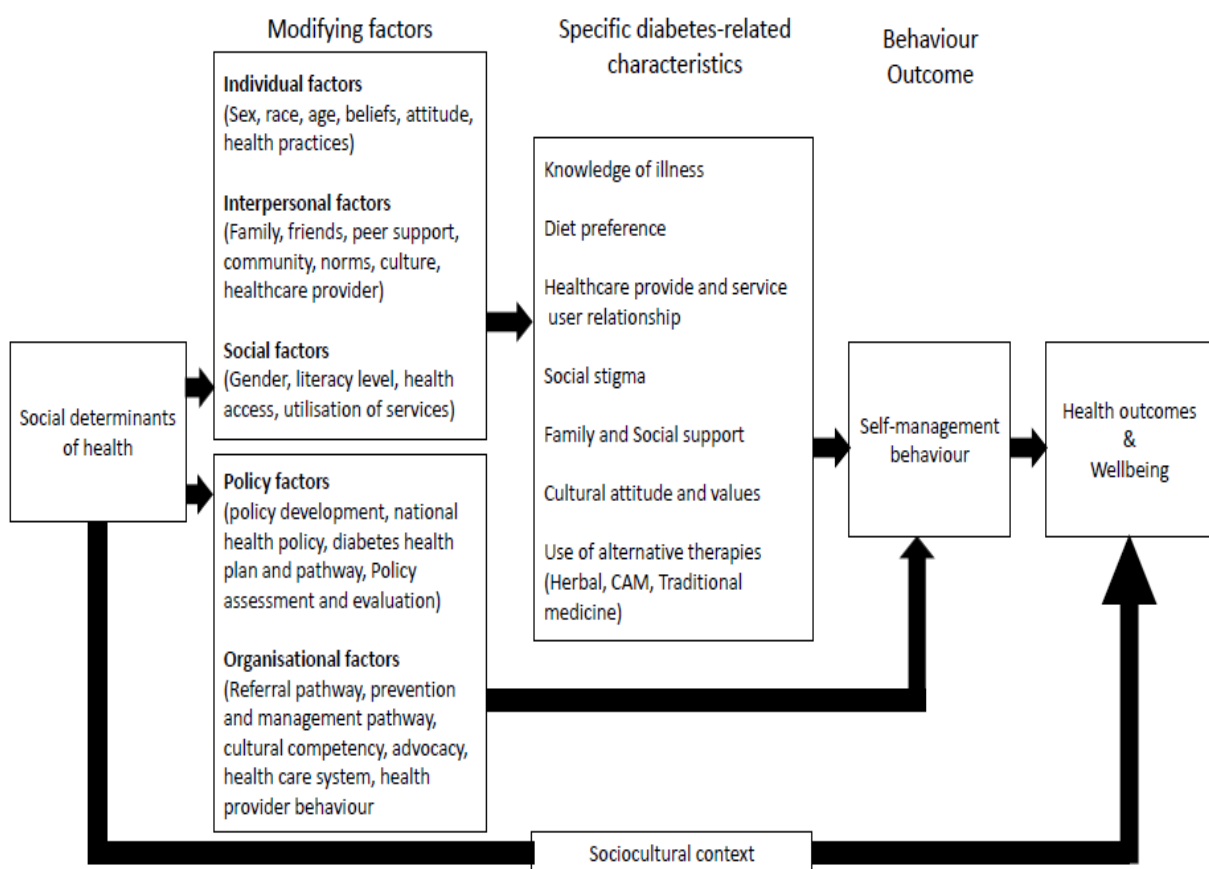


Figure 2.4. A conceptual framework for diabetes self-management (*adapted from sociocultural perspective of Sanderson (2010) and modified Mcleroy et al. (1988) socioecological framework for health promotion*)

2.9. The nature of culture in health behaviours and public health

2.9.1. Bridging culture and behavioural health

Over the years, the discourses around health and well-being have emerged as important features of contemporary societies (Nettleton S, 2013). The medical and scientific view of health has been defined as the absence of disease (Blaxter, 2004), and by contrast, WHO defined health as *“a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”* (WHO, 2005). The lay conceptualisation of health in cultural notions is more related to the social and cultural context, which defines a holistic interpretation of health. How people conceptualise health account for different health practices, social and cultural notions or context of people in a geographical location and social environment (Helman, 2007; Nettleton, 2013).

The definition of health varies throughout an individual’s lifetime and sometimes illustrates the way in which beliefs and culture give different explanations for a set of symptoms and illness. According to Nettleton (2013), health education, health management and disease prevention have different approaches from the Lay's perspectives, these vary among different groups, and gender, which is mostly accounted for by various social, the geographical, cultural and economic context of the people, lived experiences. People’s belief and behaviour related to health, illness could be somewhat culturally entrenched, and this calls for the understanding of health behaviours clearly through individuals’ beliefs and cultural views. According to Nazroo et al. (2008), a better understanding of sociocultural inequalities and their backgrounds will both increase the understanding of the causal processes and practices; creating opportunities for the development of public health policy that acknowledges cultural differences.

However, the majority of previous studies focuses solely on the influences of social, psychological, behavioural, and genetic factors, such as socioeconomic positions, discrimination, inequality in access to treatment and management regimens (Nazroo et al., 2008). Less attention has been given to the socio-cultural determining factors and practices that have led to the contemporary social and behavioural positioning of ethnic minority groups, including Black African population, and the related cultural patterning of health behaviours and outcomes. Recognizing the nature of culture and health beliefs as a determining factor in social and behavioural context, and how these relate to cultural patterning of health and health outcomes, helps with the understanding of socioeconomic inequalities and health disparities of diabetes occurrences

2.9.2. Relevance of cultural beliefs to public health

According to Helman (2007), the importance of culture and health beliefs and the contribution to health improvement and health promotion to an individual or community is essential for public health practice. Eckersley (2006) argued that the role of culture in health as a major determinant of health inequalities is highly significant in population health and well-being. Eckersley (2006) defines culture as “*the language and accumulated knowledge, beliefs, assumptions and values that are passed between individuals, groups and generations. A system that defines how people see their world and their place in it*”. (Eckersley, 2006, pp 253). Eckersley (2006) further posited that culture could help to explain health differences and health outcomes within the society and changes in population health. This includes the level of inequality, cultural values and norms and social conditions. Similarly, Stronks et al. (2013) describes culture as an important aspect of health that helps to understand how individual’s perceptions, norms, values, and beliefs that are socially and traditionally

conveyed, affect health through health-related behaviour and health care use among ethnic groups (Hruschka and Hadley, 2008; Unger and Schwartz 2012).

Previous findings highlight the complexity of culture as a health barrier. It is one of the many factors that a man negotiates to inform self-management behaviour. Eckersley (2006) argued that the influence of culture on health and well-being and its outcome has been seen more as general and not specific. On the other hand, Stronks et al. (2013) argued that it is important to recognise that the significance of culture to health-related behaviours varies between the outcome measures of culture, serving either as a protective factor (for example, religious values and beliefs that reduce unhealthy behaviours), or as a risk factor (for example, social norms that increase the risk of unhealthy behaviours and lifestyle). Baum (2008) and Stronks et al. (2013) further suggested the need for a stronger theoretical framework that could identify and specify the causal pathways that link culture and individual's perspective to a specific health outcome. Moreover, the role of a cultural explanation for health-related behaviours within a community setting should be considered in evaluation with other potentially relevant explanatory factors, including socioeconomic status (Stronks et al., 2013). In contrast, Trickett (2009) previously argued that behaviour is not only influenced by an individual's cultural activities, but also by surrounding cultural environment. Trickett (2009) emphasised that the cultural context of the surroundings, neighbourhood and general geographical areas and the demographic characteristics of the populations and ethnicity should be considered when measuring cultural influence on health.

Besides, understanding people's ideas and perceptions about health care and protection lived experiences in self-management and disease prevention can improve the effectiveness of health promotion programmes. According to Nettleton (2013), belief in and consideration of

individuals' ideas and lived experiences can act as a facilitator of health education messages in the development of health intervention programmes. For example, a health education campaign, which aims to encourage people on self-management and to take responsibility for their own health, becomes more useful if people's view and knowledge of disease causation, prevention and lived experiences of management are first understood and considered before implementation of suitable strategies. This could help people believe that they can effect change through their shared knowledge and experiences (Keeley et al., 2009; Nettleton, 2013). Trinket (2009) suggested that improved perception of cultural influences on health could lead to the development of more efficient and culturally relevant health education and promotion programmes. Moreover, the Audit Commission (2000) previously suggested that seeking individual and community views should consider major requirements for an appropriate diabetes service for people, having a policy for detecting diabetes in high-risk groups, giving advice sensitive to culture and health belief differences and increase awareness and health interventions among high-risk populations. It is essential to understand both individual and community views and their comprehension of the innovative programmes presented by HCPs and policymakers in order to have improved participation in health intervention programmes. Therefore, it seems plausible that identifying the modifying factors and barriers to health behaviours among high-risk populations through sociocultural research can provide a useful and acceptable intervention.

It is as important to evaluate the significance and interpretation of health and illness for both health sufferers and other lay people in society to understand the experience of disease, ill health and health comprehensively. However, Nettleton (2013) argued that the significance and interpretation that an individual place on health and illness could be influenced by other factors including socioeconomic and social-political perspectives of health. This could be

because the demands of healthy living and improved health outcomes is evident in all aspects of life. Thus, in that respect is the demand for a holistic approach to health and healing, which encompasses the larger representation of positive health and well-being and healthy lifestyle (Nettleton, 2013). According to Nettleton (2013), the concept of health needs to be explored by considering lay perspectives, which are rather non-professional or expert knowledge-based. This holistic model of health help in examining the knowledge of disease prevention and the understanding of how people manage their health, which could also be shaped by their pattern of lifestyle and behaviour that can be regarded as potential risk factors associated with their health status.

2.10. Observed research gaps in reviewed studies

Although several qualitative studies have identified various risk factors, including; family history, unhealthy diet, physical inactivity, ethnicity, obesity, impaired glucose tolerance, increasing age on T2D, few have focused on the influence social and behavioural factors in diabetes care and self-management. They have also not attempted to understand the impact of culture and health beliefs on adherence to treatment or behavioural change among Black African populations from the perspective of people living with T2D. Furthermore, previous studies have identified knowledge gaps in the interpretation of diabetes, disease progression, diabetes self-management and education to predominantly include the medically structured programme. However, the contextual factors, which are cultural-centred experiences and knowledge regarding engagement in self-management of T2D, health behaviours and lifestyles, are unknown in Black African population perspective. Moreover, statistics and epidemiological report have been generalised for an African and Afro-Caribbean population with less focus on the BsSA community.

Furthermore, previous studies that have focused on interpreting diabetes intervention and health outcomes have shown limitations in their approach because they are medically oriented and reported. There is less attention to the individual's perspectives and experience of health and illness. Studies, which are not conducted among people Black Sub-Saharan communities may have limited relevance to this population. This suggests that there are limited qualitative studies investigating people's lived experiences of T2D self-management among the Black sub-Saharan communities in the UK. In particular, the studies completed to date have focused mainly on cultural beliefs as a barrier to self-management of diabetes, and have been exclusively studied among South Asians and the African Caribbean communities. This study explores the perspective of people living with T2D among BsSA communities and looks into how culture plays a significant role in self-management behaviours.

2.11. Summary

This chapter assessed the current and existing literature, looking at cultural values and health beliefs in self-management of T2D, exploring the potential relationships between these factors to identify a theoretical framework with which to recognise the impact of culture and health beliefs in diabetes self-management among Black African populations with T2D.

In summary, findings from these studies have shown different factors that can influence diabetes-related management behaviour, hence the need to explore further the sociocultural understanding of diabetes self-management in terms of culture and health beliefs among high diabetes risk population. However, there is limited literature on diabetes health disparities among BsSA communities, and previous studies have not captured the full range of how cultural and health beliefs affect diabetes self-management behaviour among these communities in the UK. Such a study will help in understanding the underlying knowledge of

health disparities and perception about diabetes self-management among BsSA communities. Therefore, this study will be looking in-depth into the lay socio-cultural beliefs and attitude of people with T2D in terms of healthcare and management behaviour of diabetes.

As observed in the literature, awareness, understanding and knowledge of culture and health beliefs and the impact in diabetes self-management behaviour is significantly lacking in some ethnic minority group like Black African population. Addressing this perceived shortfall will, therefore, help to provide recommendations, which will enhance the overall delivery of diabetes self-management and healthcare services to BsSA community.

CHAPTER 3

CULTURALLY-TAILORED APPROACH FOR T2D MANAGEMENT: MOVING FROM PATIENT-CENTERED TO PERSON-CENTERED

This chapter aims to review the literature pertinent to diabetes as a significant public health issue within the policy agenda for Black African communities in the UK. It also explores how the preconception of diabetes prevention and management are viewed from a policy and professional practice perspectives. The section presents the possible risk factors that have been recognised to contribute to the prevalence of T2D among the Black African population, compared to the rest of the population in the UK. Furthermore, current policies and strategies implemented for NHS diabetes intervention will be identified, and insight into the debates on various policy responses to T2D will be discussed. The policy implication of certain diabetes management theories will be explored, and barriers to effective intervention within policy agenda will be examined. Finally, the significance of cultural approaches to diabetes behavioural change will be discussed.

3.1. Diabetes on the policy agenda

The policy agenda describes formal decisions or plans of action that has been taken by or has involved government, organisations or organised community. Policy can be made at local level, national and international levels, requiring grades of compliance and enforcement to achieve a goal (Earle, 2007c). The policy process is divided into a series of phases in a continuous cycle, starting from a speculative phase at which policymakers identify and define the nature of a problem to a speculative end at which a policy has been implemented and an evaluation of the policy made to allow policymakers to deliberate on the effectiveness of the policy before deciding the next action (Cairney, 2012: See figure 3.1). The issue of diabetes

has become a matter of priority on the policy agenda, with England being recognised as one of the countries that have a population-wide strategy for tackling diabetes (Agyemang et al., 2009). Similarly, Sharma et al. (2014) explained that tackling the issue of T2D among Black and Minority ethnic group (BME) is a national government priority, leading to a new drive to reverse the increase in the rate of T2D within high-risk populations by ensuring that every individual can maintain a healthy lifestyle and healthy self-management behaviour. However, these priorities have been placed on the work of Public Health England to help reduce obesity and overweight, which are major risk factors for diabetes (Gatineau et al., 2014).

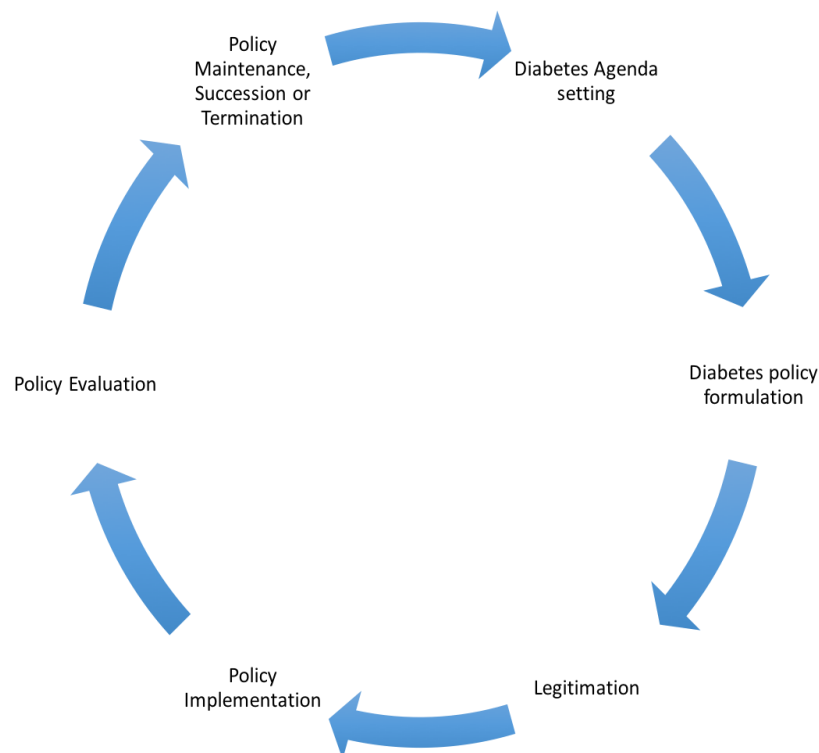


Figure 3.1. The generic policy cycle (Adapted from Cairney, 2012)

The policy frameworks highlight the need for HCPs, who are working alongside people from the BME group to provide more transparent information on how to improve health outcomes

among these communities. It also provides a basis for guiding public health strategies that have been implemented for the reduction in the prevalence of diabetes. The public health community-driven approach for the prevention and management of diabetes is of great importance and has been advocated in recent years, especially among T2D high-risk populations. There is the global acceptance that different factors outside the health system contribute to health and wellbeing. WHO (2011) recommended that the development and implementation of diabetes prevention and effective management strategies should target factors contributing to the increased prevalence of diabetes and obesity, and barriers to lifestyle change at personal, environmental and socioeconomic levels. The development of policies and intervention strategies should therefore actively involve a wide range of stakeholders and other significant bodies at different levels (international, national and local) for improved health outcomes. In such a way, public health issues like T2D can be effectively addressed by adopting a holistic approach and health promotion strategies as a global tool. Adopting this approach could help in empowering individuals and communities at risk to take necessary actions for their health, promoting intersectoral action to build healthy policies in all sectors and creating sustainable health systems at different levels (international, national and local levels).

Policies are developed at both national and local levels in the UK to tackle the risk and incidence of T2D especially among the BME communities (DH, 2013). These policy structures are underpinned by a shift in emphasis towards reducing inequalities and achieving improved outcomes among populations at risk of developing T2D (Sharma et al., 2014). Mapping the policies at different levels illustrate the way in which different aspects of the health system and intervention strategies can be effectively monitored and assessed. Moreover, the focus on local level intervention provides opportunities for local authorities,

health and wellbeing board (HWB) and NHS clinical commissioning groups (CCGs) to shape services and care to meet the needs of the population they serve to improve health outcomes (Naylor et al. 2015). The CCGs have already taken significant steps in this commission at the local level. For example, the Nottingham CCG has commissioned 'Self-Help Nottingham' to enable peer-led groups for people from the BME communities with long-term conditions, and recommissioned diabetes services for the BME communities (Bashir et al., 2016). Although Bashir et al. (2016) study show that self-help groups are effective for the people who use them; most Black African communities are not accessing them adequately. Salway (2014) argued that the limited research on ethnicity, cultural experiences and health beliefs fails to represent the needs of the BME groups. On the other hand, Naylor et al. (2015) suggested that it is important that the CCGs and NHS England regional teams engage with the public health agenda by working with local authorities to address the wider determinants of health.

The local authorities assemble the Health and Wellbeing boards to help coordinate the activities of the commissioners (Humphries and Galea, 2013). These commissioning support units provide a scope of services to CCGs and NHS England to help them perform effectively. On the other hand, Clinical commissioning groups (CCGs) are responsible for much of the NHS budget. Naylor et al. (2015) report stated that NHS England shares these responsibilities with CCGs in most part of the country through commissioning activities, though the extent of delegation varies between CCGs.

3.2. Diabetes as a priority Public Health issue among Black African populations in the UK

T2D remains a key public health issue in the UK, especially among high-risk populations, such as the people from Black African origin. There is increasing concern about the health

and well-being of the affected population (Diabetes UK, 2016a). More significantly, the problem of diabetes among Black African populations is likely to continue and have long-term adverse effect and impact on the health and well-being of individuals if person-centred actions are not taken to reverse its development (Harrison, 2014). The issue with T2D has been associated with lifestyle factors; including, diet, and lack of exercise, family history, health education, cultural practices, self-management and social influence (WHO 2011; Diabetes UK, 2016b). A range of underlying cultural, socioeconomic and language barriers further complicate low awareness of T2D in the community (Harrison, 2014). This can include the reluctance to acknowledge illness as a major problem, an unwillingness to start early treatment or alter unhealthy dietary habits and behaviours (Bashir et al., 2016). Therefore, T2D prevention remains an essential contemporary public health priority on the UK policy agenda. This intervention involves addressing the key drivers including social, cultural and environmental factors. Without an improved understanding of these key factors and the identification of effective intervention strategies to reduce the prevalence, T2D will continue to be a major public health issue prominent among high-risk populations.

3.2.1. Medical versus social construction of diabetes

Illnesses can be expressed and represented biomedically, socially and culturally depending on the meaning attributed to them (Conrad and Barker, 2010). Diabetes is constructed medically when an asymptomatic person begins to show key biological signs and indicator of increased sugar glucose level in the blood (Diabetes UK, 2004), which is found through laboratory test or routine medical examination. Yudkin and Montori (2014) emphasised that diabetes as a global epidemic had been medically constructed for the benefit of the clinical community due to the increase in the clinical incidence rate and medicalisation of treatment given to people having this health condition over time. The clinical examination of PLWD means that

diabetes becomes more clinically recognised thus ensuring that figures and statistics about this condition are known to make plans for HCPs, imminent diagnoses and treatments for clinical symptoms of diabetes or diabetes-related complication (Diabetes UK, 2015b). The compliance perspective approach which focused mainly on maintaining blood glucose through diet, exercise, oral medication and insulin, has been criticised. This is because the complexities of an extended self-management regimen and practices are not acknowledged (Macaden and Clarke, 2010). There is the possibility of HCPs neglecting other important sociocultural factors while focusing on individual compliance with treatment and advice may lead to poor diabetic control. This biomedically focused self-management is prevalent in most diabetes literature, and the need for people to comply with the expert HCPs advice is vital (Rhee et al., 2005; Khunti et al., 2012). The term 'self' in self-management has been ignored in the process of intervention, and the person is objectified as the 'patient' (Koch et al. 2004). Conversely, the biomedical view of 'patient' compliance often fails to recognise the individual's voice in making decisions about their condition. Therefore, when the individual refuses treatment, do not comply with the regimens or uses other health care remedies, they are often perceived as exhibiting non-compliant behaviour.

Clark (2014) argued that medicalisation paradigm reveals the priorities of the global health agenda, reflecting the different values placed upon the role of individuals, the health system and government. Also, the responsibilities of the private sector including industry on the advancement of health solution. During the last two decades, there has been a rise in medical research and media representation of the prevalence of obesity as a socially constructed and growing epidemic among high-risk populations (Moffat, 2010). Moreover, diabetes has been intensely studied with the massively increased rates of obesity identified as one of the major risk factors (Gatineau et al., 2014). Nevertheless, Yudkin and Montori (2014) argued that the

adoption of the western diet and lifestyle are the dominant factors that have greatly affected the prevalence of diabetes epidemic around the world. Consumption of highly processed foods and fats also contribute to unhealthy lifestyles and the development of T2D (Yudkin and Montori, 2014).

Social construction emphasises the sociocultural aspects of the issues of health and illness experience (Conrad and Barker, 2010). The social construction of health addresses the broader influences on health (Social, cultural, environmental, economic and political factors) rather than focusing only on disease composition. It moves beyond the focus on lifestyle and conduct. The social construction of diabetes deals with such issues as people's decision to reveal their illness and lifestyle adaptations to cope with the illnesses (Conrad and Barker, 2010). Stigmatization of diseases and its representation has a significant impact on how an individual perceives and accepts the care and treatment he or she receives (Schabert et al., 2013). Kleinman et al. (2006) suggest that the way an individual perceives, experience, explain and cope with illness is culturally shaped by the social position occupied and disease conceptualisation. Various studies have reported on diabetes stigma and negative perceptions of the disease (Browne et al., 2013; Nam et al., 2010; Winkley et al., 2015). Deriving an understanding of how the cultural beliefs and social position conflict with biomedical care are important and paramount to the way people manage their diabetes

Diabetes is often relegated to a disease caused by an unhealthy lifestyle and lower economic status, which are independently associated with an elevated risk of obesity (Gatineau et al., 2014). This further keep people away from seeking care and support for their illness; making it worse for people to come freely to be diagnosed (Conrad and Barker, 2010). Some illnesses such as T2D are embedded explicitly with cultural meaning (diabetes - sugar disease), which

is not directly derived from the nature of the condition, but shapes how society responds to those afflicted and the individual's experience of the illness (Conrad and Barker, 2010). Influences on compliance with treatment and acceptance of the illness are individual's beliefs about the illness, medication and health care in general; their knowledge, ideas and experiences, and those of family members and friends. The social construction of diabetes simply identifies how the society shapes and is being shaped by, medical ideas of diabetes. Society's interpretation and perceptions about illness influences policymaking largely (Conrad and Barker, 2010). People are influenced a lot by the socially constructed ideas of "norms" and "patterns" of diabetes-related factors.

Relative to constructing illness experience, culture and individual personalities play a significant role in the perception and definition of illness (Conrad and Barker 2010). Culture plays a crucial role in how individuals experience illness and interpret health (Uskul, 2010). Diseases like T2D have cultural indicators that have changed over the years and determine how individual and society view and define them; however, some of these markers including diet and belief remain. Studies have focused on the extent to which people believe the cause of their illness, but the biomedical model of managing diabetes remains dominant regardless of the health beliefs and culture that influence response to treatment and care (Anderson and Funnel, 2010; Khunti et al., 2012). Having T2D has often been labelled as a chronic illness both culturally and medically as this has been identified as a major public health problem (Diabetes UK, 2016b). Nevertheless, the representative value and social concept of fatness accumulation and weight-gain differ across cultures. In certain cultures, especially in the sub-Saharan region in Africa, fatness or larger body size symbolises good health and wealthy life (Gardner et al., 2010). In contrast, fatness signifies poor health, particularly with the issues of dietary behaviours in some other cultures (Gatineau and Mathrani, 2011). Gatineau and

Mathrani (2011) further argued that the shift in the ideology and the medicalisation of diabetes has resulted in individuals being personalised for unhealthy behaviours.

A personalised approach to diabetes care has become a system of clinical trials of participants with attributes of unhealthy behaviours (Coulter et al., 2013). The personalisation agenda was considered by the NHS England to improve compliance with treatment, support people who live with long-term conditions and decrease health cost by reducing inefficiencies of trial and error dosing, hospitalisation due to complications and reactive treatments (DH, 2012). Personalisation is central to both choice and control of health, and the production of better health outcomes (Horne et al., 2013). The approach is significant in providing a link between care planning for individuals and commissioning for local populations; hence, providing a good use of local authority services (including social care and public health), community resources and together with traditional health services (Buck and Gregory, 2013; Coulter et al., 2013). Over time, this approach has been aligned to work for the care and support that people need and how it fits into their lives, providing a positive impact on quality of life and emotional well-being (Forder et al. 2012). However, many of the 'real-world' experiences of individuals are being excluded due to other commodities and factors that contribute to ill health. Besides, personalised approaches preclude the comparative nature of how health behaviours and practices are acted out as part of everyday life in a complex social and cultural context. The management and care of long-term conditions including diabetes still tend to be the clinician's responsibility rather than a collaborative endeavour with active personal involvement and effective self-management support (Coulter et al., 2013). The clinician's position often creates a context of tension in the relationship with patients. Here, social and cultural dynamic interferes with the attributes needed for the collaboration of care, including being treated like a 'person' and not a 'patient'; becoming involved together in

managing their diabetes. The perceived lack of connection on a more personal level widens the distance in the relationship of patients with clinicians. Thus, clinicians' comments are often seen as insensitive or unsympathetic because of the focus on personalised behaviours rather than personalised advice. Thus, failing to consider individual concerns, experiences or situations.

On the other hand, Yudkin and Montori (2014) argued that the social construction and medicalisation of diabetes allow people to be portrayed by society in a way that suggests unhealthy lifestyles. Studies have reported the need for a shift from an exclusive construction of diabetes based solely on biomedical facts towards the social and cultural meaning of the illness (Conrad and Barker, 2010; Yudkin and Montori, 2014). Nonetheless, the construction of diabetes as an epidemic based on medical facts and the symbolic increase over the years underpins the perception that diabetes is a major public health issue that requires greater urgency (Diabetes, 2015b).

3.2.2. Tackling T2D among the Black African population

Addressing the significant health inequalities and the risk of diabetes among Black African community's demands improvement in raising awareness, prevention, active treatment and promoting relevant intervention (Diabetes UK, 2012b; 2016a). Despite the figures on the risk of complications, a study by Diabetes UK found that less than 33% of people from the Black African descent are aware of the risk and complications associated with T2D, including heart attack, amputation, stroke and blindness (Diabetes UK, 2013). A range of complex and interrelated factors, including genetic, social, economic and cultural factors, generates this increased risk. The lack of awareness among this community has become a serious concern to the UK health system. Low awareness of T2D among this community is further complicated

by a range of cultural, social and economic factors contributing to the reluctance in acknowledging T2D as a health problem, lack of adherence to treatment regimens, unwillingness to change unhealthy dietary behaviours and lack of proper self-management (Nam et al., 2011). Addressing the significant challenge that T2D presents to the Black African community and identifying the factors contributing to the increased prevalence is substantial in the measures of prevention, early diagnosis and improved care. Some of the risk factors identified are being overweight, having a family member with diabetes, high consumption of carbohydrate diet and higher body fat levels resulting in insulin resistance (Diabetes UK, 2013). All these risk factors were identified as the most active indicators of T2D among the Black African community (Oldroyd et al., 2005; Tillin et al., 2013). Moreover, there is evidence showing that Black Africans face challenges and barriers, including deprivation and cultural background, which affect the possibility of accessing appropriate health care services (Higgins and Dale, 2009).

3.3. Development of policy and strategies for tackling diabetes in the UK

Promoting public health is a multidisciplinary endeavour that ranges from the surveillance of health and disease in a population, and its management, through to the provision of health services and empowerment of the community to improve their health (Lee-Treweek et al., 2005; Earle, 2007b). Optimizing health globally and improving the well-being of the population has moved the fundamental health areas of contemporary public health to mainstream health practices because of the concern about health inequality in the society. Public health policies emphasise the promotion of health behaviours and lifestyle among people at high risk of developing T2D. Due to the prevalence and the rising level of diabetes, related health issues and the burden associated direct cost of treatment and healthcare support services, different government policies and guidelines have been developed for healthcare

and management both globally and nationally. The World Health Organization has set up several global and regional strategies to design programmes to address diabetes surveillance, control, prevention and management (WHO, 2013a). The Diabetes Action Now was a joint effort by both the World Health Organisation and the International Diabetes Federation to stimulate and support the effective measures for the control of diabetes and increasing awareness of the disease (WHO, 2004). This is to achieve the global target of delivering safer healthcare with the overall goal of facilitating the development of a sustainable health system (WHO, 2013a). A recent study of the barriers to improving the health outcomes and diabetes-related complications in the Black and minority ethnic (BME) communities identified the significance of exploring and tailoring an appropriate and culturally sensitive approach to the specific needs of these communities (Nam et al., 2011). This study advocate for innovative ways to improve intervention, awareness initiatives and equitable access to services at both national and local levels. However, the epidemiological position of the present policies, about the prevention, treatment measures and management of certain health conditions, especially among Black African communities, remains individualistic and fragmented. This is due to a lack of consideration for the role of individual sociocultural values and community engagement.

3.3.1. Policy response to diabetes in the UK

In response to high prevalence amongst the Black African population, policies and strategies for diabetes management has become an essential part of managing the situation in the UK (Diabetes UK, 2016b). Some of these policies and strategies are National Service Framework for Diabetes (NSF-D), and Quality and Outcome Framework (QOF).

3.3.1.1. Formulation of response - National Services Framework for diabetes (NSF-D)

The National Service Framework for Diabetes (NSF-D) was published in 2001 in the UK as guidelines to improve service care of T2D. It sets out 12 national standards to drive up service quality and tackle inequalities relating to those at risk of diabetes in the UK (DH, 2001). In other words, national standards were set up to help in healthcare quality, diagnosis, screening, prevention, education and adolescent transition for people at risk of diabetes (DH, 2001). The second part of the National Service Framework for diabetes – the delivery strategy was later published and implemented to advise the government on how the standards can be provided (DH, 2003). This framework recognised that while diabetes is indiscriminate, the: *“burden of disease falls disproportionately on people from minority ethnic groups and those socially excluded from society (including prisoners, refugees, asylum seekers and people with mental health problems and learning disabilities)”* (DH, 2001: pp-2). Consequently, NSF-D calls for multi-agency interventions as effective strategies and multifaceted approaches to assist with both early detection of diabetes, reducing the risk of individuals developing diabetes and empowerment of self-care support (DH, 2003). Effective management is essential for reducing diabetes-related morbidity and premature mortality (Diabetes UK, 2016a). Some of these multifaceted approaches include the public health risk-based approach, skills-based approach, evidenced-based approach, built-in quality assurance and regular audit of health outcomes. The skills-based approach supports improved self-care knowledge, blood glucose control, weight and dietary management, physical activities and well-being (DH, 2003). Similarly, the Department of Health’s Expert Patients Programme offers people living with long-term conditions, including diabetes, the opportunities to learn new skills that could help others manage their health condition (DH, 2003). The NSF-D proposes opportunistic screening of individuals with multiple risk factors (e.g. belonging to an affected Ethnic group and a Body Mass Index indicating obesity), as an

effective strategy to assist with earlier detection of diabetes and recommends that people should be provided with structured education (DH, 2001). This was significant due to the increase in inequalities of outcomes in diabetes care. Thus, the principles underpinning the standards of the NSF-D requires the platform to be person-centred and developed in partnership with people with diabetes. Nonetheless, the services require equitable, integrated and collaborative services for a positive outcome.

The NSF-D was later updated in 2010 (DH, 2010a) to set out standards for prevention, identification, empowerment and clinical care of people with diabetes, rationales, key interventions, and analysis of the implications for planning services. NSFs-D aims to improve services for diabetes care by setting national standards. Although these frameworks may vary slightly in each control, they aim to detect, treat, plan and manage services under one framework; therefore, reducing disparities in care delivery. According to the Department of Health review, the framework standards highlight the significance of a healthy lifestyle and the importance of diabetes self-management, empowering people to be able to self-manage their diabetes (DH, 2010a). Hence, health intervention programmes and initiatives were established for early diagnosis, public awareness and to help in reducing the number of people at risk of developing diabetes over time and improving diabetes health outcome. For example, the NHS Health Check programme, NHS Diabetes Prevention Programme and Change4Life commissioned by local authorities to target people at high risk of developing T2D (DH, 2008c; Diabetes UK, 2016a). Figure 3.2 summarises the prevention and management pathway under the NSF-D (DH, 2001)

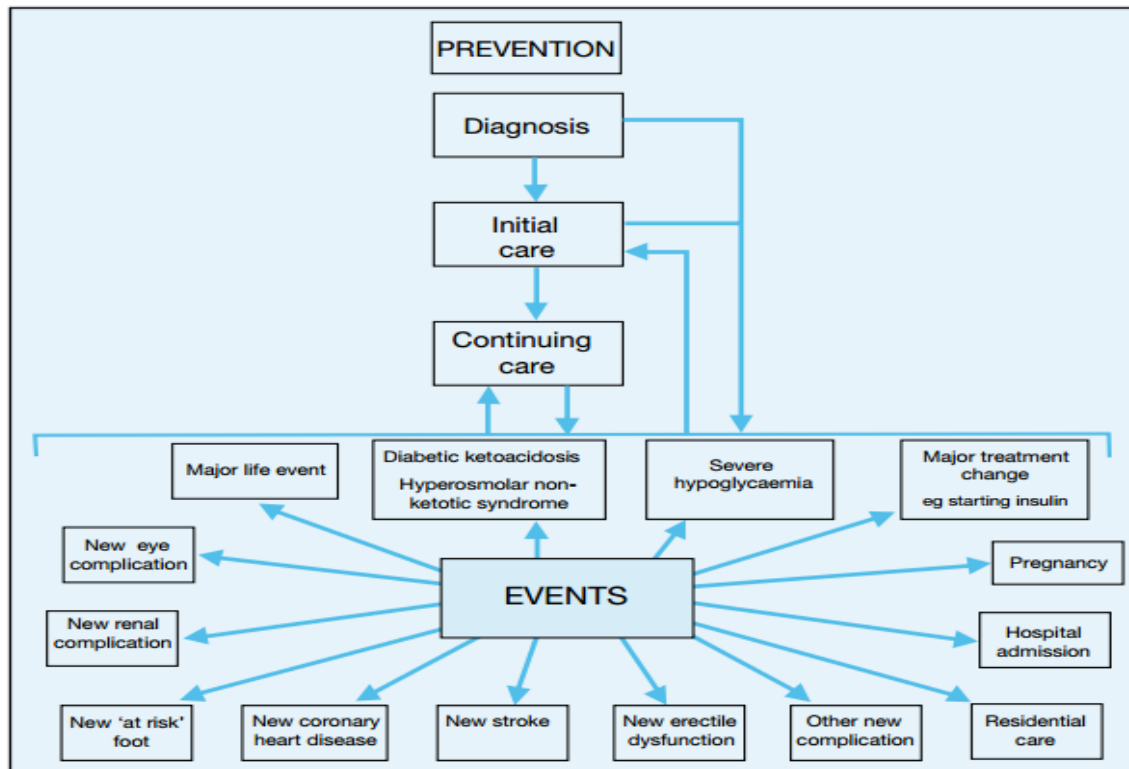


Figure 3.2. Summary of the prevention and management of diabetes (Source: *National Service Framework for Diabetes, 2001*)

The developed interventions and initiatives by the Department of Health (DH) appears to take a stance on the delivery of the NHS Plan and social care goals, with the emphasis being placed on the aspect of increased involvement of the communities and individuals in the management of diabetes care. This should lead to informed service-users making beneficial changes to their lifestyle (Foot et al., 2014). The Wanless Report emphasised the importance of people being fully engaged with their health as this could further help in reducing the escalating costs of health and care services related to the mounting burden of disease (Wanless, 2002). The policy has tended mainly to focus on or articulate ‘patient’ participation, but the idea of individual responsibilities was further acknowledged in the 2009 NHS Constitution (DH, 2010b). Moreover, Healthwatch England has been advocating health

and social care rights and responsibilities to provide a framework that would ensure that the voice of individuals and the public are heard in the health care system.

Individual's responsibilities for health reflect the expectations of how healthcare services can be used effectively and equitably (DH, 2013). Nevertheless, the impact of the NSF-D, since it was established in 2003 remains significant as records show that the rate of planning and delivery of services at the local level with the support of national coordinators for diabetes has considerably increased over the last 10 years (DH, 2011b). Although the percentage of people with diabetes, achieving all three-treatment standards improved marginally between 2009 and 2010, the underlying performance did not change between 2011-12 and 2012-13 (NAO, 2015). However, the percentage of the people registered achieving all three treatment standards for controlling blood glucose, blood pressure and cholesterol increased to 36% in 2012-13 compared to 20.9% reported in 2011-2012. The changes evolved from the feedback response of GPs (General Practice) on how information is being recorded at each GP practice (NAO, 2015). On the other hand, the underlying NHS performance in delivering the nine recommended care processes has not improved since the last recounted assessment of diabetes services. One of the reasons is the lack of evidence of the effectiveness of routine feedback and lack of delivery of integrated diabetes services, or insufficient capacity within the services to offer help to those who need the service (NAO, 2015). The UK Foresight Report on obesity and related diseases like T2D showed that whilst there are currently health policies that offer guidance, there is no sustainable solution to control the projected increase in T2D (McPherson et al., 2007; Nettleton, 2013). As such, it could be argued that these policies had little impact on diabetes prevalence. There is, therefore, the need for engagement with a diversity of strategies that encourages different approaches in health management practices for T2D. (NAO, 2015).

3.3.1.2. Formulation of organisational scheme - National Institute for Health and Care Excellence (NICE) and National Diabetes Audit (NDA)

National Institute for Health and Care Excellence (NICE) was established by the Department of Health (DH) but is operationally independent of the government. NICE provides national and public health guidance on the prevention of T2D Mellitus among high-risk groups and advice to improve health and social care (NICE, 2012a). NICE recommended that all people with diabetes should receive the nine key care processes at their annual diabetes review (NICE, 2011b). These key indicators ensure diabetes is well controlled and are designed to prevent long-term complications. The nine key tests recommended are weight, blood pressure, smoking status, HbA1c, urinary albumin, serum creatinine, cholesterol, eye examinations and foot examinations, which help to ensure that diabetes is under good clinical control and that a person with diabetes has reduced the risk of complications (NICE, 2011b). The NDA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP), and delivered by the Health and Social Care Information Centre, working with Diabetes UK (Gatineau et al., 2014). Forbes et al. (2010) review of the organisation and delivery in the UK identified that limited health research on diabetes, inconsistency in the range of healthcare support self-care behaviour provided to people with diabetes affect the health outcomes of people with diabetes. Consequently, the 'Diabetes in adults' quality standard 2011 was developed to cover the clinical management of diabetes and supports the National Service Framework (NICE, 2011a). The standard consists of 14 quality statements, including access for people with diabetes to a structured educational programme, receiving personalised advice on nutrition and exercise and an annual assessment of risk for and the presence of complications.

To meet the required standard for NICE, the structured education programmes should be evidence-based, have a planned curriculum, be delivered by trained educators, have a built-in quality assurance and regular audit of programme outcomes (NICE, 2011b). However, it was reported for the assessment that the Department of Health had not met the standards required by the National Service Framework for Diabetes (NDA, 2012); only 56% of people with T2D in England received the recommended nine annual checks. Thus, people were still developing avoidable complications; almost half of the people with diabetes did not receive the full annual checks to manage their diabetes effectively, increased number of preventable death and increase in health cost for the NHS (Diabetes UK, 2012a). Although several of the structured education models, including, Diabetes Education for Ongoing and Newly Diagnosed diabetes (DESMOND), Expert patient education programme (X-PERT) and Diabetes Manual, vary in mode of delivery, course duration, quality, there was evidence to show the effectiveness and the attendance of the programme on clinical outcomes (Davies et al., 2008; Khunti et al., 2012).

Previous studies have shown that interventions for behavioural changes can be successful and cost-effective. A pilot study on the effectiveness of Diabetes Education for Ongoing and Newly Diagnosed diabetes (DESMOND), showed that while people who participated in the intervention programme reported positive improvements in the beliefs and knowledge of their illness, there was no difference in HbA1c or dimension of quality of life at twelve months (Davies et al., 2008) and decrease in patients' participation (Davies et al., 2008; Ockleford et al., 2008). Furthermore, evidence from a randomised trial of the Expert patient education programme (X-PERT) showed that though most people with diabetes who attended the programme found it helpful. It improved glycaemic control, reduce diabetes-related complications, reduces cholesterol level, the improved requirement for medical treatment,

knowledge of diabetes, self-empowerment and treatment satisfaction (Khunti et al., 2012). Nonetheless, there was no overall improvement in the quality of life at fourteen months of participation (Deakin, 2012). Besides, Radhkrishnan (2012) study showed that hypertension and heart disease had no impact on medication adherence, self-monitoring, physical activities, smoking or diet control when tailored to structured intervention for T2D, however, an additional health funding and follow-up showed an impact on screening, dietary intake and levels of physical exercise (Frost et al., 2014; Khunti et al., 2012). Additionally, the structured programmes were found to be effective as they are cost-effective for delivering courses on diabetes treatment and management. This is because of the financial strain diabetes put on health care budget (Deakin, 2012; Gillett et al., 2010). However, the study and the intervention process reveal no cultural understanding of people with T2D and the impact this has on diabetes self-management. Thus, the intervention process and its evaluation had little or no information or indicator to identify people's culture and health beliefs as a predictor because all the guidelines are developed clinically and medically.

Despite the evidence supporting the benefits of the intervention for National Diabetes prevention programmes, the increasing adherence to NICE guidelines did not correspond to the reduction in the incidence of T2D (Ashra et al., 2015). Ashra et al. (2015) review revealed that individual elements of the guidelines show little evidence that individual factor assessed affected the progression to T2D and the only significant association reported was that the intervention sessions spread across 9-18 months lowered T2D incidence. Ashra et al. (2015) further argued that the inability to identify NICE guidelines as optimal for an effective diabetes intervention reflects the nature of building complex interventions and emphasises the need for a holistic approach to evaluating the effectiveness of the intervention. A component on its own may not necessarily affect T2D incidence or weight and glucose outcomes.

However, when an increasing number of components are harmoniously utilised together, an interactive effect may be seen, resulting in improved outcomes.

Reports from various studies on the effectiveness and response to diabetes programmes indicated that people with T2D often rationalise and prioritise their understanding and response to diabetes treatment and intervention programmes over a range of views. This includes information and support provided by their HCPs, perceived benefits of the programme (Jones et al., 2014a; Lawal, 2014), external barriers that control their perceptions of health care and continuity of individualised care tailored to their needs (Frost et al., 2014). However, Ockleford et al. (2008), Jones et al. (2014b) and Winkley et al. (2014) identified that individual knowledge, adherence to treatment and health advice and perceptions of the required responsibilities could facilitate an appropriate acceptance of education and self-management. Another view of participants identified for lack of participation is the fact that diabetes is associated with a health-related stigma; people with diabetes might not find it comfortable to tell anyone about their diagnosis or share their experiences with the health issue (Noakes, 2010; Harrison, 2014).

Different studies have provided insight into the process and demonstrated an acceptance of various diabetes intervention programmes, given the long-term nature of T2D and individual experiences. These studies had however not explicitly identified and explained the aspect of sociocultural factors that affect peoples' attitude and behaviour to treatment and perceptions to health programme offered over time. An understanding of the role and the impact of culture and health beliefs on diabetes management among the BsSA communities could promote cultural sensitivities essential for effective self-management intervention programmes for the long-term for improved health outcomes (Wilson et al., 2014). Moreover,

Kanavos et al. (2012) argued that no single health strategy has a suitable and comprehensive objective to achieve sustainable and adequate diabetes management because there is a need for more focus on multidisciplinary health care and ‘patient’ education with different content and interventions. Thus, diabetes policies, monitoring, and implementation of structured education intervention and diabetes management for the high-risk population with evidence of long-term impact are limited and inconclusive (Khunti et al., 2012). There is more focus on how people with diabetes achieved biomedical and lifestyle outcomes with control over diet and unhealthy behaviours, neglecting those minority groups with a higher risk of complications and high prevalence of the disease. According to Kavanos et al. (2012) analysis of diabetes guidelines, the main policy priorities need to be a focus on diabetes prevention, the implementation of lifestyle strategies to improve population health, investing in early detection or screening initiatives for people with diabetes and pre-diabetes and enhancing cooperation with HCPs to avert severe complications. While Kavanos et al. (2012) identified the importance of diabetes guideline development that encourages evidence-based practice, Patel et al. (2015) and Nam et al. (2010) studies emphasised on the need for a more culturally tailored care and treatment intervention to inform behavioural change for people with T2D. Thus, T2D as a growing health problem requires a broader perspective to improve management and prevention of diabetes among high-risk populations.

3.3.2. Current strategies and methods for tackling diabetes in the UK

3.3.2.1. Public Health Outcomes Framework (PHOF)

The Public Health Outcomes Framework 2012 was published by the Department of Health (DH, 2013) with the aim of improving and protecting the nation’s health and well-being. It also seeks to improve the health of the population; which should increase life expectancy and

reduce the differences in life expectancy and healthy lifestyle among communities (DH, 2013). Considering diabetes is a significant public health issue, the PHOF refocus the whole Public Health System around achieving positive health outcomes through intervention and initiatives for the population at risk of diabetes and reducing inequalities in health, rather than focusing on process targets (ibid). The introduction of the PHOF was a drive to encourage public health delivery collaborations to make significant improvements in services (ibid). One of the key public health activities relating to the prevention of diabetes includes the NHS Health Check programme and the NHS Diabetes Prevention Programme.

The disciplines of health promotion and public health have begun to integrate a multidimensional concept of health into practices and multidisciplinary approaches to diabetes care (Ham et al., 2012). It is no longer a just health intervention of diagnosis and treatment, but more about educative prevention, effective and sustainable service. There is no doubt that the World Health Organisation's (WHO) SDGs (Social Determinants Goals) have been influential in driving forward the reorientation of health systems towards recognising the value of a preventative and integrative approach to health. This includes the socioeconomic influences on health, and the development of health strategies that encourage social and economic investment within communities that are most at risk of diabetes (WHO, 2013a). Similarly, the National Service Framework and National Institute for Care Excellence (NICE) have previously identified the importance of multidisciplinary team intervention, including dietary advice for diabetes management (DH, 2003; NICE, 2011a). Moreover, WHO emphasised the need for partnership to provide a system that addresses the social determinants of health to achieve a sustainable health development (WHO, 2015). Initiatives such as the Healthy Cities Movement and Health for All 2000, which arguably had limited successes, nevertheless refocused attention on the need for inter-sectoral collaboration

and partnership using multi-disciplinary frameworks in wider society and at a local level. The introduction of a culturally tailored and locally led system in the intervention process allows community responsibilities for the improvement and protection of the public's health (DH, 2011b)

Public Health has moved away from the emphasis on individual lifestyle change and health education towards more radical social models of community development, a public-private partnership, pre-post treatment assessment and actively challenging power structures and policies (Ham et al., 2012). This perspective sees the health system as practically the same as social, economic and political development and has become known as health development. The public health system in the UK, however, remains structurally positioned within the biomedical based knowledge of health. This has created tension between the relevance of biomedical power and control of public health agendas, partly through its assertion that epidemiology and scientific based reformation is the main discipline of public health. Although responsibility for the public health system in the UK moved into the local government in 2013, the intervention remains medically informed. The NHS remains critical to protecting and improving the population's health by delivering public health services and promoting health through all its clinical activities (DH, 2013)

3.3.2.3. Joint Strategic Needs Assessment (JSNA) and Joint Health and Wellbeing Strategy (JHWS)

The Joint Health and Wellbeing Strategy (JHWS) sets out the Health and Wellbeing Board's vision and priority to access and address the impact of diabetes on health and well-being of local communities (Diabetes UK, 2014c). The health and wellbeing boards (HWBs) were

established in all 152 local authorities in 2013 (Diabetes UK, 2014c; Addicott et al., 2015) to promote integrated working between the NHS and local government. The boards are responsible for the commissioning of services and for health decisions that meet the strategic needs of the population. They also incorporate care at the local level through their responsibility for producing a Joint Strategic Needs Assessments (JSNA) and Joint Health and Wellbeing Strategy (JHWS) (Diabetes UK, 2014c). The JSNA locally assesses current and future health and social care needs that could be met by the local authorities, City Council, Clinical Commissioning Group (CCGs) or NHS England. Conversely, the JHWS is developed to meet the needs identified in the JSNA. These strategies play key roles in supporting the health and well-being of people at risk of developing T2D. This is by promoting behavioural change for a healthier diet and more active lifestyle and improving the identification, care and treatment to reduce costly and life-threatening complications and disabilities (Diabetes UK, 2014c). The policy intention of the strategies is for the health and - boards to consider wider factors that affect their communities' health and well-being and local assets that can help to improve outcomes and reduce inequalities (Marmot et al., 2010).

The local authorities support the Health and Wellbeing Board decision on understanding the needs of the local communities by providing the evidence of health and well-being outcomes, which inform the JSNAs. This further drives a collaborative approach to the commissioning of improved health and care services that will improve the health and well-being of local people. Although the resources and focus of delivery of service of the diabetes strategy are at the local level within which the Department of Health has the overview of national standards, the Department of Health has been distant from the implementation process. There is substantial evidence that people with diabetes often find that their care is fragmented and that their needs are not met in a coordinated way (Humpheries and Curry, 2011). Such advances

at the local level, therefore, provide remarkable opportunities for improving health and well-being with fully coordinated care, and for people to take control and manage their health behaviours (Humphries and Galea, 2013). Local authorities are however required to interpret and analyse data and information for several functions, including giving public health advice to the Clinical Commissioning Groups (CCGs). Nonetheless, as the primary JSNA and JHWS duties sit jointly with local authorities and CCGs, the local authorities have the opportunity of using their expertise to support partnership operating between organisation represented on the health and wellbeing boards (Humphries and Galea, 2013). On the other hand, Public Health England (PHE) provides support for local authorities in delivering locally appropriate interventions and services (PHE, 2013). Also, they provide data, interpretation and evidence to enable local public health teams to improve the public's health. PHE further provides support and resources to local authorities, which enables them to identify local issues and make the best decisions in reducing health inequalities and improving health outcomes for the local community, including vulnerable groups (ibid). However, budget constraints on health programmes and campaigns limit the ability of the people to support and benefit from medical innovation, and there is a risk that medical advances, which may further fuel demand for care, as such innovations extend the range of individual's eligibility for treatment (Robertson, 2016).

The JHWS sets out a long-term agenda for improving health, good social outcomes, and promoting healthy behaviours and modifying risk factors for those diagnosed with, or at risk of developing diabetes. Health and wellbeing strategies have been seen to be positioned for addressing the challenges of diabetes, the impact it has on local communities and ensuring that people at risk of diabetes are supported to manage their condition. However, over 40% of local health boards in England tasked with improving the health and well-being of their local

communities are failing to prioritise T2D prevention by giving no account of the prominence (Humphries and Galea 2013; Diabetes UK, 2014c). This has given rise to the number of people with the condition and the associated cost of it on the health and social care system (Humphries and Galea 2013). Nonetheless, many of the strategic actions needed lies beyond the sphere of the health and social care system (Addicott et al., 2015). Individuals, families, communities, the voluntary sector, the private sector, the education system, and all levels of government share responsibility for improving health and well-being and preventing and tackling the causes of avoidable diabetes complication. Thus, improving diabetes care and prevention to keep people at risk well for longer and reducing the burden on health and social care, requires a more rigorous action that could reflect the enormity of diabetes. Similarly, the King's Fund review (Addicott et al., 2015) identified that ageing population and increased prevalence of chronic diseases such as diabetes require a stronger reorientation of consistent primary care and orientation towards prevention and self-care.

The outputs of evidence, analysis of needs, and agreed priorities, however, determine the actions that local authorities, local NHS and other stakeholders need to take in order to meet the health and social care needs of the people and to address the wider determinants that impact on health and well-being (Marmot et al., 2010). Nonetheless, the definition of evidence has been contested within the field of public health (Beenstock et al., 2014). Evidence could imply local intelligence focusing on needs, which is a considerably narrower definition than that what is understood by most public HCPs; which includes systematic reviews and analysed qualitative or quantitative data (Rychetnik et al., 2004) although what counts as evidence in public health has been contested. An advantageous description of different forms of evidence is proposed, and evidence to support public health action could include the 'citizen's voice' and incorporate a community perspective (South et al., 2014).

Effective public health intervention needs reliable data to reflect the need for services at local level. Hence, public health evidence ought to include wider perspectives that can contribute significantly and prominently to decisions about the effectiveness of the strategies and address the significant challenges to improving health and well-being among vulnerable groups.

3.3.2.4. Action for Diabetes

The Action for Diabetes in NHS England initiated by the 2014 diabetes review report set out the strategic direction for healthcare services for PLWD to reduce the inequality in the risk of developing T2D and for prevention of T2D (NHS England, 2014). Action for Diabetes outlines several priorities that cut across the five domains of the NHS Outcomes Framework (See Figure 3.3). These domains are; making personalised and integrated diabetes care a reality; reducing diabetes emergency admissions and empowering people to manage their diabetes safely; ensuring everyone with a long-term condition has a holistic, personalised care plan, and improving health literacy (DH, 2011a; NHS England, 2014). This model describes a whole system approach to managing diabetes where an informed individual, engaged HCPs, informed commissioning and organisational processes are brought together to deliver personalised care plans that recognise the unique needs of each living with diabetes (Coulter et al., 2013). It also promotes a public health approach to primary prevention of T2D, is aligned with the Department's 'Making Life Better' Strategic Framework for Public Health and 'A Fitter Future for All 2012-2022' the obesity prevention framework.

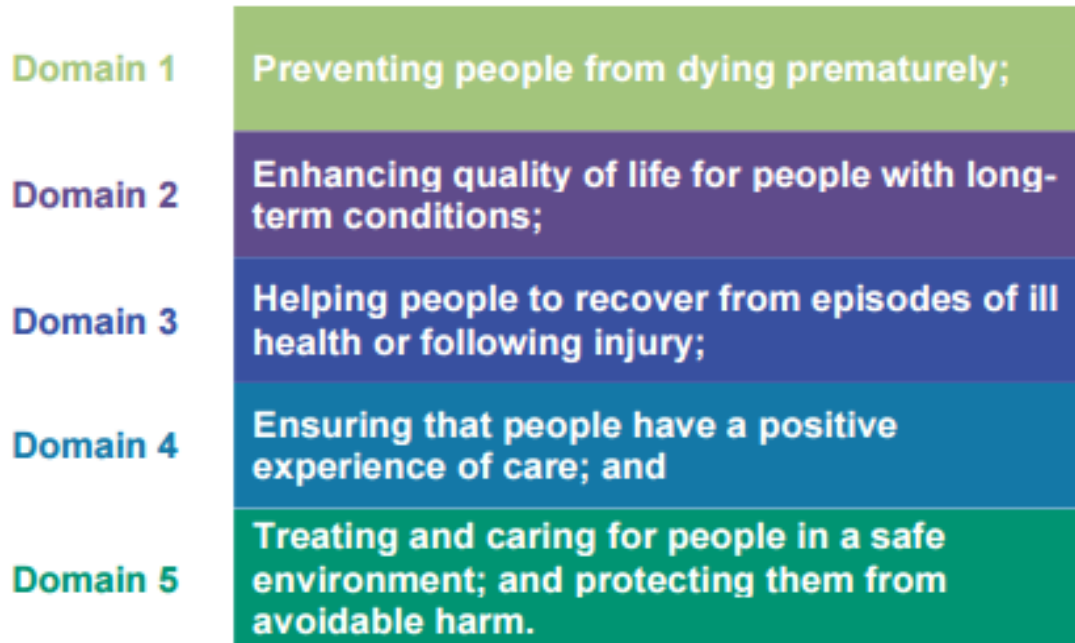


Figure 3.3. Five domains of NHS Outcomes Framework

Source: NHS Outcomes Framework 20011/12 (DH, 2011a)

3.3.3. Implementation of policies and strategies

Over the years, the UK health policies have aimed at improving the health outcomes and social care of population at both national and local levels (DH, 2013). Thus, it is evident that there is now a changing focus on diabetes care from the traditional biomedical model, which concentrate on early recognition, and treatment of diabetes to a preventative model. Thus, focusing on improving primary prevention through raising awareness and promoting early diagnosis through uptake of risk and screening assessments among high-risk communities (DH, 2010a, Diabetes UK, 2013). Diabetes policies and prevention programs are typically designed to change diabetes outcomes, equal access to care and resources, and reduce the risk of diabetes-related complications. As mentioned earlier in the chapter, some of the examples of the diabetes strategies that have been implemented include the NHS Health Check and Healthier You: the NHS Diabetes Prevention Programme (NDPP).

3.3.3.1. NHS Health Check, 2009

NHS Health Check remains a fundamental tool in Public Health England commissioned intervention and prevention approach to tackling the prevalence of diabetes (DH, 2010a). The NHS Health Check is a health check-up for adults aged 40-74 living in England that assesses early signs of stroke, kidney disease, heart disease, T2D or dementia (PHE, 2013). The programme supports people to manage that risk through individually tailored advice (DH, 2010a). The NHS Health Check system identifies eligible people for the diabetes prevention programme and addresses the social norms and obesogenic environments that increase the level of risk of T2D (DH, 2010a). However, partaking in the NHS Health Check does not guarantee that people won't get a serious health problem like heart disease or stroke; it only identifies the risk of occurrence and not associated lifestyle behaviours that could impact on the risk. (PHE, 2013) Besides, an individual may be falsely reassured by the results or advice on a medical test. For example, the overall risk score might be recorded as better than average even though the body mass index (BMI) or cholesterol is high due to other lifestyle factors.

Although there is evidence that the NHS Health Check efficiently identifies and supports people at risk of developing CVD and T2D (Robson et al., 2016), only 46% of those diagnosed with T2D received all the required 8 care process on the programme (PHE, 2018). The PHE report indicate out of over 15 million people eligible for the NHS Health Check nationally, only about 2.6 million people were offered programme, and only 49.91% of those offered take up the programme (PHE, 2017d). The data for Nottingham showed that out of 77, 298 people eligible for the programme, only 6,234 people were offered the programme, and only 48.09% of those offered take up the programme (PHE, 2017d). Although Robson et al. (2016) study shows progressive year-on-year improvement, the report from PHE shows that over half of all the people offered the NHS Health Check do not take up the programme

(PHE, 2018). Evaluation of these reports indicates the need for an integrative and community engagement approach that could improve the uptake of the programme, especially at local level.

3.3.3.2. Healthier You: NHS Diabetes Prevention Programme (NDPP), 2016

The NHS Diabetes Prevention Programme (NDPP) is a joint initiative with Public Health England, NHS England and Diabetes UK that aims to deliver services on a large scale NHS England, 2016). This programme identifies those at high risk of developing T2D and offer them a lifestyle intervention incorporating group educational sessions that would promote weight reduction and physical activity (NHS England, 2017). This programme is done mainly in the form of group sessions of lasting 1 to 2 hours and delivered face-to-face for a minimum of nine months. Correspondingly, various studies have demonstrated how health behaviour intervention programmes can significantly reduce the risk of developing diabetes through promotion of healthy weight and physical activities (Gilles et al., 2007; Dunkley et al., 2014; Ashra et al., 2015). NICE guidelines (NICE, 2012a) recommend that people at high risk of developing T2D are offered referral to a local, evidence-based, quality assured intensive lifestyle-change programme. Therefore, the NDPP identifies people at risk of developing T2D and refer them onto a behaviour change programme offering tailored advice and support that could help people increase their levels of physical activity, improve diet and gradually lose weight to reach and maintain a BMI within the healthy range.

There is substantial evidence about the impact of diabetes strategies and lifestyle interventions in the UK having a positive influence on T2D outcomes and prevention activities (Ashra et al., 2015) However, there are only a handful of studies looking at the lived and living experience of self-managing T2D on an individual and community level,

from a mainly sociocultural context. Although the reduction in the progression of T2D was substantial, reductions seen in the secondary outcomes were small. (Ashra et al., 2015). In general, these programmes look at proximal factors, competing for demands on patients' time and resources, living as 'uninsured patients' and how these issues could be addressed by policy and professional practice. These studies use homogeneous samples to highlight individual behaviours and the barriers that relate solely to people on a clinical report or geographical variation. The more knowledge that is heterogeneous may, however, give a clearer picture of how other determinants contribute to the successful management, better health outcomes, and the role of culture and wider socio-contextual issues in T2D self-management.

3.4. Critical analysis of current UK policy response to T2D

3.4.1. Discourse of individual responsibility and behaviour change - personalisation

Following the Ottawa Charter for Health Promotion (WHO, 1986) and changing economic and political circumstances, policymakers and HCPs have developed behavioural change interventions to cope with the growing prevalence of long-term diseases such as diabetes. In the context of UK diabetes policy, policy development has shifted towards increased responsibilities of people for their behaviour and health choices, including dietary health (DH, 2010b). The emphasis on self-management as part of a wider discourse of the public health agenda emphasises the importance of individuals taking active responsibility for their health and well-being (DH, 2010b; Diabetes UK, 2016a). People with T2D are encouraged to adopt healthy behaviour and lifestyle to maintain health outcomes. For example, self-managing chronic illness to reduce the risk of developing complications and considering their actions and activities as a major contributing factor to their health and well-being (Patel et al.,

2016; Diabetes UK, 2016a). Healthy lifestyle and behavioural practices, particularly those related to diet and exercise are individual factors that can affect health outcome (Diabetes UK, 2016a). Therefore, it is assumed that the risk of complications can be greatly reduced if diabetes is properly managed individually. Lorig and Holman (2003), who describe self-management as an individual's responsibility for day-to-day living, management of chronic disease and adopting healthier behaviours, also identify the concept of individual responsibility. The intervention process has however been predominantly medically focused; less attention has been given to other social determinant factors leading to the cultural patterning of diabetes outcomes. Brown et al. (2007) discussed how treatment and prevention of T2D remain clinically and medically driven, though an emphasis on quality and outcomes tend to be commissioned within the community. As previously discussed, this could be based on the idea that diabetes is a medical condition that should be treated medically. Hence, the actions of individuals with diabetes become subject to the moral approval of their lifestyle and the awareness of the cost of health care.

The DH report (DH, 2005) suggests that individuals with long-term conditions require support. This support was based on different levels of care needed depending on the stage of the condition. It identified three levels of care for people suffering from long-term conditions such as diabetes, based on the Kaiser Permanente model to illustrate the complexity and progressive nature of the long-term condition. These different levels of care are; disease management for those individuals who are high-risk, individuals with multiple and complex conditions and self-care support for low-risk patients (70-80% of those with long-term conditions) (DH, 2005). According to the Department of Health, self-care is defined as '*the care taken by individuals towards their health and well-being*'. It involves actions taken by individuals to live a healthy lifestyle and to deal with the impact of any long-term conditions

on their daily lives; to meet their social, emotional and psychological needs; and to prevent further illness or complications (DH, 2005).

Self-care support is provided through several initiatives and interventions in the UK. For example, the development of new technologies, information, skills training (such as the Expert Patients Programme) and support from HCPs, and self-care support systems (DH, 2008b). These programmes are designed to be individualised and specific to a person's need and circumstances, based on the understanding of an individual's belief and the level of knowledge. The implication is that people can minimise the risk of complications and other illnesses, and improve a healthy lifestyle by simply identifying with their responsibility for individual health outcome. However, despite cost-effectiveness of the intervention programmes, the impact of the large-scale self-care support interventions designed as population-level public health measures, such as the Expert Patients Programme and the NHS Direct Self-Care Guide, has been constrained by limited engagement from patients and professionals (Kennedy et al., 2007a). Many of the health programmes have been criticised for focusing on a relatively narrow biomedical knowledge lens. Also, the transferability of such programmes to people with low health literacy and complex personal or social circumstances has been questioned (Hinder and Greenhalgh, 2009; Taylor and Bury, 2007). On the other hand, Oldroyd et al. (2005) emphasised that assessing the impact proves difficult, especially among individuals from BME communities who may not necessarily obtain the care and support that they require (Oldroyd et al. 2005).

The current health policy for self-management of T2D, which is a multifaceted public health issue and a growing health problem, particularly among the Black African community, has been increasingly constrained to a medical and clinical model. It reflects a medical

perspective that is more patient-centred. However, preventive, treatment measures and management of this condition in this group remains fragmented due to a lack of consideration of the role of culture and lay belief system encompassed within a holistic and preventive approach to health (Coulter et al., 2013). Cultural background and identity, often creating disengagement with formal health care and services (Uskul, 2010; Khunti et al., 2012), influences Black African responses to diabetes treatment and management. The broader aspect of making people responsible for their health and wellness remains more epidemiological based, less culturally driven and informed in terms of the intervention process of diabetes management. This further shows policy being weighed down by the complexity of diabetes as a multifaceted public health issue.

Another part of the discourse is that efforts have been made at the policy level to shift the balance of power away from medical HCPs and medical model towards a more multi-disciplinary base that includes patient's knowledge and narratives that are disempowered because of professionalisation (Nettleton, 2013). In the new public health agenda, HCPs are persuaded to treat patients as equal partners in the decision-making process relating to their care, treatment and management (DH, 2008a). However, there is little recognition of both the current imbalance of power due to professional dominance on health care policy at both the local and national levels. There is also a need to address this need for cultural awareness in professional attitudes if it is to have any real effect on diabetes management. Attempts by government to modernise public health and open it up to broader multi-disciplinary perspectives, away from professional medical dominance, have been consistently nullified by public HCPs exerting strong occupational and professional control (Evans, 2003). Anderson and Funnel (2010) argued that medical professionals find it difficult to allow patients to make their own decisions as their professional culture and training authorises them to be in control

of clinical decisions and information. Consequently, the field of public health and diabetes management, in the UK, is characterised by a mismatch between the rhetoric and the implementation of policy, and public narratives of individual experiences (ibid).

The focus on individual responsibility in health care needs to shift the emphasis of chronic health problem like diabetes as being solely caused by poor lifestyle to the understanding that cultural factors and social inequalities may lead to poorer inequalities (Taylor and Bury, 2007), and vulnerability of the high-risk population. Consequently, there is the need for policies to shift focus away from individual influences alone and seek the potential impact of the wider sociocultural factors on health (Baum and Fisher, 2014). Although T2D has risen on the policy agenda in recent years, challenges of individual experiences and awareness of cultural influences remain inadequate. It is important that public health initiatives for ethnic minority populations such as the BsSA communities reflect equal potential effectiveness and sensitivity to the needs of the communities in order to reduce health inequalities. Efforts to improve care for people with a T2D need to shift away from the reactive, bio-medical and fragmented model of medical care towards an understanding of the lay concept of diabetes that is shaped by sociocultural perspectives (Uskul, 2010). This has the potential to become key parts of public health policy and strategy that could be more proactive, cohesive, holistic and preventive in its approach (ibid). This approach could be significant in reducing the increased burden of diabetes long-term complications. It can likewise assist in improving health services to reach them more responsive to the cultural and societal contexts of diabetes self-management. By incorporating the sociocultural perspectives in the diabetes care provision and management, there is a higher recognition that the role individual or lay narratives can improve the assessment and implementation of policy initiatives. This can shift or challenge professional power and the medical model of diabetes intervention.

Furthermore, health care policies should be understood as the product of health intervention; not just of the efforts and intervention of HCP, and development in medical science research, but also of a wider process of social, cultural, economic and political change in the health sector. The Marmot Review in England (Marmot et al., 2010) is part of the Government's response to the recommendation of the Commission on Social Determinants of Health by WHO (CSDH, 2008). It demonstrates the Government's commitment to reducing health inequalities in England by contributing to the development of a cross-government health inequalities strategy post-2010 (Marmot et al., 2010). The review includes policies and interventions that address the social determinants of health inequalities; going beyond interventions designed to change individual behaviour, with an early year's focus and taking a life course approach. There is the need to understand that personal choices are made in a context of larger social determinants of health (Marmot and Wilkinson, 2005; Nettleton, 2013). It should also be noted that effective policies implemented for health promotion and prevention programmes, and designed appropriately for high-risk groups and culturally sensitive could improve health outcomes.

3.4.2. Behavioural transition: 'The Expert Patient.'

The perception that 'patients' who are affected by diabetes need to be educated and active in the prevention or self-care of their chronic illness is characterised in the Expert Patient Programme (EPP) (DH, 2001; Diabetes UK, 2010). The Expert Patient Programme in the NHS diabetes framework was adopted as a self-care option for individuals with a chronic long-term illness such as T2D to be trained to manage their condition within a medical model (NHS Choices 2013). Firstly, the person with diabetes is recognised as the 'main actor' in managing their condition. Secondly, they are empowered to reduce the severity of their

diabetes symptoms and work in 'partnership' with NHS professionals in self-managing their condition more effectively (DH, 2005). This programme is designed to contribute to 'treatment' decisions based on their expertise on how regimens of self-care might best fit into their lives. The diabetes education programme promotes a healthy lifestyle and improves health beliefs (Davies et al., 2008; Khunti et al., 2012). Despite the evidence supporting the benefits of the diabetes programmes, the concept of 'expert's knowledge' remains debatable as it remains subjective to health care practitioner's instructions and clinical measures. Rogers (2009) argued that diabetes programmes are associated with strategies for reducing the demand for NHS services, hospital admissions and care that includes extended roles of HCPs. In the case of the EPP, the role of the 'patient' as an 'expert' is extended so that they become less dependent upon health services and more expert in self-managing their illness. Similarly, Paterson (2001) suggests that despite adopting the idea of 'patient' empowerment, professionals continue to position themselves as the sole authority in clinical decisions in health care rather than adopting practices that fully enables 'person' empowerment. The relationship and interaction with HCPs thus become 'meetings between experts' (Fox and Ward, 2006). Though studies in the UK suggest that diabetes education sessions such as the Expert Patient Programme have the potential to reduce hospital admissions and improve health outcomes, assessments to date have been uncertain about the impact of these programmes on the use of healthcare resources (Rogers et al., 2009). Rogers et al. (2009) concluded that people face tensions and dilemma between the aims of the programme and their own lived experiences.

The notion that 'expert patient' manages their chronic condition as directed by practitioners indicate an irony that "patient expertise both assumes compliance and a degree of taking control of the management of health" (Fox et al., 2005, p. 1300) by evoking 'empowerment'

that emanates from the dominant ideologies such as the medical model. Although the National Service Framework for Diabetes (DH, 2001) and the report on "Structured Patient Education in Diabetes" (DH, 2005) acknowledge that PLWD has expertise in their self-management, the undertone of biomedically focused treatment and care remain present. Individuals still require self-managing their illness in line with HCP's instructions and biomedical guidelines. The HCPs continue to hold expert knowledge about the illness and can only approve an individual's self-management behaviours if they are in line with this expert knowledge. Knowledge of illness emphasises the perceptions and experiences of the individuals with the condition, therefore, are not only connected to biomedical diagnosis (Conrad 1987) but with other social determinants of health. The issue of compliance with treatment presents a further challenge to productive interactions between service users and providers. Hence, Montori et al. (2006) emphasised that patient-centred instruments of 'clinical governance' might undermine care. Similarly, Salmon and Hall (2003) theorised that handing over responsibility for the disease to the individual releases professionals from the inevitable failure of managing a disease they cannot cure. Thus, professional authority is maintained by claiming to enable "empowerment" (Salmon and Hall, 2003). From this perspective, the healthcare practitioner's role is in providing education and empowerment that allows the person to make informed decisions within the context of his or her life experience. Hence, it is essential to draw more attention to the individual, cultural and other contextual factors that shape people's health beliefs, experience and self-management behaviour.

It is evident that the WHO's recommendations and strategies for integrated care and patient-centred services influenced the direction of UK health services for those dealing with long-term conditions such as T2D (WHO, 2015). Nonetheless, the challenge for policymakers in the UK remains apparent in developing strategies that would sustain the principles of public

involvement, individual participation and treatment decisions for people with long-term conditions (Goodwin et al. 2012). Although the shift in care is enshrined in words like ‘public involvement’ and ‘patient participation’, the traditional model of medical care still prevails because long-term conditions like T2D are being treated based on a medical model (Blaxter, 2007). The word ‘Patient’ is often used in the medical model, and this denotes some element of power dominance in the relationship; problems and needs are identified by the service provider. Hence, the individual is promoted to a passive recipient of care rather than as an individual who can express his or her own needs and choices.

3.4.3. Nutritional transition – changes in diet and eating pattern

It is essential to make constant decisions about what to eat, how much to eat, and when to eat it, ideally depending on individuals’ choices, affordability and availability of the food. There has been a movement away from traditional staples, including street foods, from local markets to more fast food from increasingly globalised food companies with larger access to readily available processed westernised food (Popkin et al., 2012). The shifting dietary patterns like increased consumption of an energy-dense diet high in fat, particularly saturated fat, and low in unrefined carbohydrate, has been influenced by changes in the world food economy, growing economic and social development (WHO, 2008; Popkin et al., 2012). Nonetheless, there has been a reduction in energy expenditure, associated with sedentary lifestyles, labour-saving devices (both at home and at the workplace), motorised transport, the leisure activity that is often dominated by physically undemanding pastimes and increased access to technology (WHO, 2008). The complex interplay between biological factors and these energy imbalances exacerbates many health problems such as T2D and obesity (Gluckman et al., 2011). As people progressively interact with the municipal environment and corresponding forces of globalisation, growing cultural and economic behaviours due to

modernisation and convenience heavily influences the consumption of foods outside of the home (Black, 2016). The effects of moving to an obesogenic environment, where over-consumption of highly processed food is prevalent, is further compounded when we consider the damage that has been done prior to migration, by poor nutrition and eating patterns, which has been shown to lead to noticeable increases in T2D (Popkin et al., 2012). These shifts and transition contributed to the increased prevalence of diseases and increased the cost of healthcare. Such changes have been well documented for people from the Black Minority groups in the UK and are found in varying manifestations in many developing countries.

Dietary patterns that characterise individual choices, which are not necessarily positive outcomes, are rationally based essentially on individual desires and beliefs. The consequential changes in food affordability, availability, preparation and eating behaviour matter greatly in lifestyle changes for people living with T2D. Another driver to the shifts in the eating pattern is the increased biased reporting about appropriate diets in the media. People are often exposed to centralised information and misguided perceptions about traditional diets, and major pushes to promote certain dietary patterns, especially to reduce the risk of diabetes-related complications. As a result of some of the misleading information about certain dietary and lifestyle changes, there has been the further increase in diet-related diseases such as T2D, cardiovascular disease, hypertension and several different cancers, as well as body composition among the Black African population (Tillin et al., 2012).

The impact of dietary patterns and transition have been linked to increased risk of developing T2D in several research studies (Brown et al., 2007; Esposito et al., 2010). The considerable diet and lifestyle pattern affecting the Black African community result from the transition from a predominantly farming environment with access to basic - and often unprocessed

foodstuffs, to a modern environment where food is more plentiful and processed, requiring reduced labour (Gilbert and Khokhar, 2008). Many African migrant households in the UK with T2D have moved from a position of absolute ownership of choice of diet to recommended diet from HCPs, the significance of which often affects the eating pattern and cooking methods (Gatineau and Mathrani, 2011). People from African origin have been shown to adopt western dietary and lifestyle patterns by eating more junk, processed foods in exchange for their traditional diet. Although there are difficulties assessing the impact of dietary patterns on the development of nutrition-related non-communicable diseases among British Africans, previous studies often assemble data from different ethnic groups from the African origin together, such as 'Black African and the Black Caribbean'. The demographics of people of African origin covers a wide group of populations from the sub-continent. They experience different social and cultural factors, have different religions and variable dietary habits and cooking methods. Consequently, maintaining the sustainability of dietary information provided by doctors and other HCPs, HCPs need to take a broader perspective so that their responsibilities and information extend beyond service users to the local population (Gatineau and Mathrani, 2011). NICE recommends that policies and health programmes be tailored to local communities, as people have different needs and barriers to behavioural changes, especially eating pattern, to effectively reduce the risk of diabetes (NICE, 2014).

3.4.4. The professionalisation of the health care system versus lay perspective

Lifestyle modification often requires behavioural change and knowledge of individuals. This should employ a lay perspective; explore the culture and health beliefs of the individual and to identify the gap in knowledge and barriers to change. It should then prioritise the risk factors that need addressing while increasing individual confidence and self-efficacy. According to Taylor (2007), the importance of lay involvement and cultural knowledge

contribution to health improvement by communities and individuals is essential for public health practice. Frankel et al. (1991) defined lay's perspective of health as "*the process by which a person interprets health risk through routine observation and discussion of illness and death in personal networks and in the public arena as well as from formal and informal sources such as television and magazines*" (Frankel et al., 1991, p. 428). Understanding people's cultural experience of their health and ill-health and how it is affecting their daily lives can provide essential knowledge for public health practice (Williams and Popay, 1994; Taylor, 2007), which aims to achieve sustainable health (Baum, 2008) for a high-risk community. Taylor (2007) identified ways that lay's perspective and cultural experiences can be of great value to public health in helping people promote their health and well-being and to reduce health inequality in society. Lay knowledge can help to give insight into different patterns of behaviour and lifestyle that influence people's health. This can consequentially help to determine new areas for investigation in relation to mortality, and disease and reformation of existing policies and strategies (ibid). It can also help to understand the factors that underpin and create health inequalities (ibid). Furthermore, it can help to understand how people live and manage their lives in different circumstances, which is important in understanding how health intervention and support can be offered effectively and efficiently to promote people's health and offer sustainable behavioural change (ibid). It can also stimulate people's interest in actively being involved in implementing and monitoring any health improvement programmes for maintaining their health and well-being (ibid). Nevertheless, this can only be achieved by engaging people's knowledge and views about their health and illness fully into any health intervention required.

Public health action to promote health and well-being can be made more efficient by accepting lay's contribution towards health. However, the opinion of medical experts is seen

as inflexible and professional, and the medical representation of illnesses is becoming a rather unacceptable language to lay people generally because of individuals' beliefs and culture (Kham, 2012). Therefore, lay people seek to pursue strategies and interventions that are more consistent with their cultural values; a sense of belief and personal reflections (Nettleton, 2013). Lay's perspective and cultural experiences are being a form of public health proficiency that helps people to establish their right to have their experience of managing their health and illness be equally valued (Taylor, 2007). Lay perspectives are important health perspective to HCPs to ensure that health intervention and health improvement are made effective in the society (ibid). HCPs should be aware of the value of and respect the ideas, of lays perspective in relation to health and illness (ibid). Nonetheless, the active involvement of people with T2D in the self-management process requires the provision of effective, support and education that recognises the importance of the individual's culture, belief and lifestyle.

Nevertheless, Warwick-Booth et al. (2012) argued that though the medical model faces criticism of individualism and reductionist understanding of health and prescribed medication, it has some distinct advantages including advancement in health technology and scientific knowledge of the nature of health, forming the basis of many healthcare provision. Medical interventions and treatments have become the dominant tools to halt or reverse the disease process (Armstrong 2000; Taylor 2007). Although the sociological model is essential in health promotion in terms of viewing health holistically, the concept of health and healing still relies on the expertise and scientific understanding of health and illness (Kelly and Charlton, 1995). Though this reductionist approach has been useful in advancing medical knowledge, Freund et al. (2003) argued that it could miss the broader dimensions affecting people's health and well-being. Earle (2007a) suggested the sociological model of health

should be used mainly as an underlying philosophical approach to health and a guiding principle for health intervention.

On the other hand, Schoenberg et al. (2009) suggested that the criticised perception of biomedical dominance might be because biomedical practitioners' knowledge may conflict with patient life activities and constraints the understanding person's lived experiences of health. Uskul (2010) argued that people might find it challenging to accept medical perspectives and feel that their belief does not fit into the medical beliefs endorsed by HCPs, which subsequently affect their health behaviour and relationship with their HCPs. Similarly, Lupton (2003), Schoenberg et al. (2009) and Uskul, (2010) argued that Clinical medicine, HCPs and diabetes educator remain highly reductionist and continue to put more emphasis on lifestyle change, diet, exercise and medication adherence. It gives little attention and consideration for other sociocultural, psychosocial factors and lived experiences that contribute to the changes and determines health status, thereby depriving patients of a comprehensive approach to diabetes management and other health problem. These arguments further advocate the need to examine lay views and narratives about diabetes self-management, comparing them with the view and perspectives of medical experts to understand how the interpretations differ in cultural position.

It is not surprising that the diabetes policy standards call for a 'patient-centred' approach to diabetes self-management. Delivering this, however, depends on lay narratives, experiences, and people's voice, therefore, there is a constant need for a culturally sensitive approach to health intervention and education. This could help empower people with diabetes to self-manage their illness efficiently and maintain effective communication with HCPs. T2D self-management is multifactorial, considering other modifiable risk factors, including obesity,

physical inactivity, smoking and high blood pressure (WHO, 2017). A multidisciplinary approach to self-management, which is 'person-centred' and promotes empowerment, is essential to maximise the health outcomes for individuals with T2D (Ofori and Unachukwu, 2014). Factors that may influence diabetes self-management are individual disease knowledge, health beliefs, treatment options available, nutritional advice and awareness and this suggests a holistic perspective to diabetes self-management intervention as to promoting healthy behaviour, lifestyle and well-being (Diabetes UK, 2009b). A person-centred approach to T2D management and commitment to individuals' sociocultural needs tend to encourage healthy management. It also aids them to adopt a healthy practice and lifestyle, which could then guide the shared clinical decision-making process. Ofori and Unachukwu (2014) study established that holistic framework using a sociocultural approach and lay perspectives promotes health perceptions and supports healthy lifestyle decision. Therefore, it is essential for people with T2D to be actively involved in the decision and management process of their illnesses. This approach, also, promotes interventions that support people to take greater responsibility for improving their health and well-being.

These reviews, however, call for a sensitive cultural approach to policy that will address diabetes in all its complexity in the aspect of self-management. As mentioned above, the biomedical model has been dominant in modern medicine in both treatment and management of a disease. A central argument in this study is that lay's knowledge and interpretation, as a holistic approach to health management, creates knowledge of living experience that can potentially promote health outcome and behavioural change (Handsley, 2007; Kwam, 2012). Lay's perspectives and experiences should be concerned with decision and policy-making on diabetes self-management and the collective approach to other public health issues associated with the high-risk population. This approach needs to occur subjectively at individual levels.

3.4.5. Bureaucratic nature of the mainstream health system

Another view of the nature of the health care system, which has been identified as affecting health management behaviour because of the formulation of health policy on disease treatment, is the bureaucratic nature of the operational and delivery system for HCPs (Pearce, 1996; Nettleton, 2013). There is some literature alluding to the negative impact of bureaucracy in the healthcare service (Malin et al., 2002; DH, 2010b; Government Equality Office 2011). Laverack (2009) argued that HCPs find it hard to use empowerment or bottom-up approach that includes population or Lay's perspective in their epidemiological and biological study. This is because most public health intervention programmes are developed and practised in a top-down approach. Laverack (2009) further discussed that the rise in the biomedical study had formed a position of dominance within the public health bureaucratic hierarchy by controlling the efficiency of health intervention through scientific knowledge.

Furthermore, there has been a gap in knowledge because of the continued rooted professional power in the hands of the medical elite, which consequently obstructs holistic care (Zamanzadeh et al., 2015). It also hinders the improvement of lay's perspective and experiences in health management behaviour (Nettleton, 2013). For example, some HCPs often do not have the freedom to perform the certain task independently as this will require a superior observation and examination to avoid major changes in the treatment process (Zamanzadeh et al., 2015). Furthermore, the government often directly or indirectly funds procedures in health intervention and diabetes education. They are more dominated by biological or medical knowledge, which also represents professionalisation in a context that does not allow non-professionals to participate in the programme consistently. The holistic aspect of health care allows lay's perspective and acknowledges the interdependence of social and cultural needs, but is often overlooked because of professionalism and excessive focus on

the medical model (Zamanzadeh et al., 2015) This exposes patients to severe pressures, prolonged hospitalization and increases treatment cost from the NHS (Olive, 2003). Besides, Scrimshaw (2012) argued that health programmes fail to be efficient and sustainable when HCPs and policymakers do not consider people's perceptions, indigenous beliefs and behavioural parameters essential to understanding health efforts.

From the public policy point of view, the continued professional dominance of the health care system in the UK is because of the influence of the British Government in managing the scientifically based opinion on the efficacy of people's experience of illnesses (Saks, 1994). Saks (1994) argued that the professional dominance of the UK healthcare system should be playing a role in sustaining a state-supported health care system that accepts lay's perspectives and experiences in decision-making. The lack of access to new sociological research and community intervention programmes due to lack of funds affects HCPs' accessibility and commitment to real information about health and illnesses provided from within the community. In contrast, Cobden et al. (2010) and Buxton (2006), argued that maximizing clinical effectiveness has broadened the value of health care. It has led the mainstream use of economic models in evaluating diabetes through employing data from large clinical trials and epidemiological studies to determine disease progression and future cost. These can consequently result in the risk of oversimplifying patient compliance with effective treatment and healthcare by the government and medical professionals (Schoenberg et al., 2009). Furthermore, Frost et al. (2014) argued that to achieve long-term sustainable self-management strategies, people with diabetes should be provided with informed support and overall sense of empowerment in managing their diabetes. They should also be involved in the health management procedures that are appropriate for their beliefs and perceptions. Frost et al. (2014) further suggested that this inclusion enables individuals to develop flexible

and achievable diabetes management strategies that facilitate quality of life and long-term health outcome.

3.5. Identified barriers to effective intervention within the policy agenda for behavioural change

Public health campaigns in the UK have played a significant role in attempting to solve diabetes prevalence through behavioural change (Ham et al., 2012). However, public health intervention programs have had limited success in tackling the rising prevalence of diabetes among the Black African population. Development and implementation of prevention strategies are aimed at targeting common factors contributing to the rising prevalence of diabetes. Hence, barriers to behavioural change at individual, community, socioeconomic and environmental levels should be an area of concern for policy agendas, as well as actively involving multiple levels of different sectors and stakeholders. Although lack of understanding of the Black African groups by HCPs and other service providers has been identified as a major challenge, several other barriers to effective intervention have been identified for discussion.

3.5.1 Lack of culturally sensitive intervention involving key players from the communities.

Previous studies identified lack of cultural understanding of Black and minority ethnic groups by HCPs and programme coordinators as a barrier to successful behavioural change. There is a gap in the knowledge and understanding of religious and cultural beliefs, and how they affect health and health-promoting activities (Grace et al. 2008). Grace et al. (2008) emphasised the importance of cultural understanding and its impact on the motivation for

organising facilities that are appealing and acceptable to specific groups. Culture differs between individuals and communities across times and places. It can be influenced by elements of other cultures and social environment, such as the western culture, and is affected by gender and social, economic status. Thus, it should not be considered as a static phenomenon.

The underlying theory for a culturally sensitive intervention is this; if policymakers are involved in prioritising, commissioning, communicating and using research, then their unique perspectives will improve the quality and relevance of the intervention among the community. Although policymakers are interested in regularly involving 'patients' and the public, there are indications that diabetes funded projects and programmes do not reflect the cultural issues that individuals and communities perceive as priorities (Harris et al., 2015). A range of different literature indicates that some diabetes programmes have regularly involved PLWD at various stages of designing and delivering interventions at a local level. However, the level of involvement and the specific challenges encountered in diabetes research among Black African communities have not been reviewed, and lay voices are still guarded by professional authorities. There is limited information about community involvement in designing or delivering interventions for people with diabetes. Nevertheless, other studies suggest that lifestyle interventions for diabetes in the UK are both effective in behavioural changes and cost-effective (Gillet et al., 2010; Frost et al., 2014; Khunti et al., 2012). However, to maximise the efficiency of these interventions among minority ethnic groups, the barriers to healthy lifestyle changes and culturally sensitive interventions need to be identified and understood, so that health disparities these groups suffer can ultimately be reduced. Public involvement, such as using key community players in developing the intervention may have a positive (or negative) effect on the efficiency. However, no research

has explored the relationship between community involvement and empowerment for self-managing diabetes. The value of community involvement in health intervention, cannot, therefore, be reviewed without exploring the practices and their relative contribution to an individual's experience.

An essential aspect of cultural tailoring of health intervention is distinguishing between the meaning of culture and how they differ between people. For example, physical activities can be viewed a part of everyday life in African perspective, rather than activities undergone within a built establishment (Netto et al., 2010; Koshoedo et al., 2015). In some African cultures, reducing the fat content of a meal in family events could incur shame on the host or be a sign of disrespect to the guest. Therefore, dietary changes need to consider the symbolic cultural implication of certain diet regimens. The idea of a 'balanced meal' or 'healthy meal' could be meaningless to some Black sub-Saharan African community, who value the consumption of meat above vegetables and dairies. According to Lawton et al. (2006) and Netto et al. (2010), the conceptual basis for a health intervention needs to match the needs of the community. Therefore, the intervention needs to be immersed in the culture from inception, attending to expressed needs of the community and delivered through that community.

3.5.2. Social disparities in behavioural pathways

T2D prevalence, especially among Black and minority ethnic groups, is associated with measures of cultural identity, norms, attitudes and beliefs; with the most deprived community being more at risk of diabetes-related complications and higher rates of cardiovascular diseases (Tillin et al., 2012; Diabetes UK, 2016). The behavioural and lifestyle explanation of T2D focuses on how the people make their health choices and how those from the lower

socioeconomic groups often have the tendency to adopt the lifestyles that are damaging to their health (Baum, 2008); increasing the risk of diabetes-related complications. However, the impact of low-socioeconomic and social-cultural factors on lifestyle choices and diabetes-related complications can be challenging to tackle through policies without a reduction in poverty levels and awareness of cultural identity. Previous studies have demonstrated that people with a lower socioeconomic status because of personal circumstances and environmental settings, are more susceptible to the incidence of T2D and unhealthy behaviour (Gulliford et al., 2004; Diabetes UK, 2006; Graham, 2009) resulting in inequality in health outcomes. However, what is less understood is how Black African population perceive diabetes management in terms of their socioeconomic status and how policy maker and HCPs take that on board.

The impact of socioeconomic circumstances and lifestyle on disease measure differs among the Black and minority population and other ethnic groups in the UK (Diabetes UK, 2006). Socioeconomic factors, including limited financial resources, lack of resources to meet basic health needs in a particular area, ease of access to health services and referral bias have been identified as affecting the accessibility and affordability of individual diabetes treatment and self-management regimens (Diabetes UK, 2006). While some people can manage their diabetes effectively, others may find it difficult due to inadequate access to health care resources, competing for survival demands and other social, economic and cultural barriers related to poverty status, and this may result in further long-term diabetes-related complications (Bachmann et al., 2003; Vest et al., 2013). Similarly, Bachmann et al. (2003) study emphasised that people who are least educated and financially challenged are more likely not adhering to diabetes education or treatment regimen compared to those that are higher financial earners and are well educated. On the other hand, APPGD (2015) report

identified that the majority of the BME people with diabetes had not been given equal opportunity to participate in diabetes education due to lack of awareness or referral bias. This inequality was related to the availability of diabetes-related courses locally for people depending on the allocation of the postcode lottery.

Another key barrier identified was the challenge of locating health programmes where participants might find easily accessible and convenient (APPGD 2015). For example, people often find it financially challenging to travel long distances to attend the alternative programme if diabetes courses are not available in their locality. Also, many people who could not take time off work due to financial constraints or social responsibilities at home find it difficult to attend courses that require substantial time off work during the week (APPGD 2015) Therefore, it can be argued that socioeconomic status can have a major impact on diabetes management behaviour due to accessibility to, and affordability of, health care services.

Cyril et al. (2015) study show that deprived communities are not frequently approached or efficiently engaged in services provided by health interventionists to improve their health. Moreover, deprived groups are disempowered and unable to participate in health promotion programmes wherein individuals might be supported and motivated to take control over unhealthy behaviours (Cyril et al., 2015). The lesser engagement of people from lower socioeconomic backgrounds in intervention-based programmes may contribute the social disparity, therefore causing a barrier to effective intervention (WHO, 2008). Accordingly, policymakers and practitioners should ensure that diabetes prevention does not increase existing inequalities of intervention (WHO, 2012). The focus of diabetes prevention

programmes should be ensuring that the complexity of inequality is addressed by prioritising the inclusion of disadvantaged communities and social intervention, together with understanding the broader cultural context of wellness and the different mechanisms that lead people on low incomes to engage in unhealthy behaviours (Benzeval et al., 2014). Mulgan (2010) recommended that understanding the cultural differences within communities might help to tackle health inequalities more effectively.

3.5.3. Concepts of compliance and adherence

Adherence and compliance with HCPs' advice and guidelines have been much researched in terms of how best to improve the uptake of interventions (Fenerty et al., 2012). These two terms are becoming more debatable and strongly criticised due to the implication that the professional is telling the people what to do and how to manage their health, and if they fail to adhere or comply, they are liable for deterioration in their health (Keszthelyi and Blasszauer, 2009). Arguably, people are seen to behave more impulsively to advise when faced with the challenge of carrying out required health behaviours in different social situations or cultural environment. As discussed previously, the issues of certain habitual behaviours and cultural identity are likely to affect people's ability to change behaviour (Mulgan, 2010). Biomedical interpretations are selectively incorporated into understandings of illness, which, are also informed, by a person's experience and perspectives of being ill within their social and cultural context (Nettleton, 2013; White, 2016). The recent NHS policy focuses on joint decision-making between service users and service providers and patient-centred care embracing the idea of the concept of concordance, which refers to reality as the 'lifeworld' of the patient (Bissell et al. 2004). Specifically, the necessities of people's experiences need to be considered by HCPs so that agreed objectives can be developed to

enhance health care. This supports Bissell et al. (2004)'s conclusions that patients need to be involved at all levels of care, including the pattern of interventions. In contrast, the medical voice reflects 'technical interest' and a 'scientific attitude or power', which tends to strip away other social and cultural context of health and illness.

3.6. Improving the quality of diabetes intervention programmes and strategies

Prioritizing the health needs of people in the community may lead to a process of redesigning and commissioning a suitable healthcare intervention and service for PLWD in the UK. For the transformation to be successful, however, an emphasis should be placed on person-centred expertise and empowerment of those engaged in maximising their contribution to community health and well-being. Thus, enhanced level of integration is necessary for both HCPs and service users to communicate and collaborate efficiently and effectively to improve health outcomes for people with T2D. The lack of integrated team causes a more reactive rather than proactive approach to diabetes management. For instance, dieticians review people with T2D based on biomedical guidelines and report, while a nutritionist who works outside the NHS domain provide detailed information and advice to their clients based on a holistic review, promoting patient's engagement and patient self-management.

3.6.1. The role of culturally-led approach to diabetes self-management

Given the support roles that appear essential to the Black African community, there is a gap in expectation. HCPs use strategies that challenge diabetes-related beliefs and culture and provide support and information for those involved in helping patients' self-manage, to reduce the burden on the National Health Service (Vara and Patel 2011). Information and beliefs have been mistaken in terms of causes and other risk factors, treatment and

management of T2D. There is the need to promote the skills, motivation and feelings of empowerment of people living with T2D in order to change their lifestyles. This process would uncover opportunities for both the person living with T2D and their HCPs through community networks to have a common understanding of the tasks involved for effective diabetes control (Van Esch et al., 2014; Patel et al., 2015). Furthermore, developing culturally sensitive education guidelines for HCPs on how to interpret diabetes-related beliefs could identify the barriers to effective self-management and accessibility to diabetes care services (Phillips et al., 2012; Zeh et al., 2016). This could also provide a way for culturally sensitive health care and inform behavioural change in primary care for people living with T2D. Medical practices may also benefit from other sociocultural research into a direct comparison of diabetes-related illness beliefs and social networks between ethnic minority groups and the general population in the UK. Understanding the underlying reasons for people's disengagement with diabetes intervention programmes and people's cultural experiences with self-management could help to address the problem of the prevalence of T2D among the Black African population in the UK. It could also help in designing appropriate and culturally sensitive policy responses to health and well-being. Therefore, it is important to investigate and explore how people with T2D self-manage or engage with the help and collective support from others based on their identity, beliefs and the role of culture. This may further help to provide insight into how diabetes self-management among BsSA communities and their impact on health outcomes can be better supported to enable better self-care practices and well-being.

3.6.2. The necessity for cultural sensitivity in diabetes policy agenda - PEN-3 Model

Historically, the intervention used to address health issues in various cultures have been developed based on western culture and biomedical values that focus more on individual

health practice. Hence, health issues embedded in cultural practices are being overlooked, and the strategies implemented fails to achieve maximum results in addressing health behaviours. PEN-3 public health cultural model moves beyond individualistic approach used in addressing health behaviours. PEN-3 Cultural Model was developed to address the role of cultural influences in adopting health behaviours and to centralise culture in the development of health promotion intervention (Airhihenbuwa and Webster, 2004). The PEN-3 Model was designed to incorporate cultural values and practices of a specific population as part of the public health intervention for health issues like diabetes. It lays emphasis on collective health behaviour rather than individual behaviour (Airhihenbuwa and Webster, 2004; Iwelunmor et al., 2014) while acknowledging that individuals' perceptions and actions are building blocks for constructing health beliefs that are reproduced to express their cultural beliefs (Airhihenbuwa, 2007). The model is framed into three domains (see Figure 3.5): cultural identity, relationships and expectations, and cultural empowerment (Airhihenbuwa and Webster, 2004). Constructs of these domains are derived from health promotion and health behaviour-change models such as the Health Belief Model (see figure 2.3), Social Cognitive Theory (see figure 2.4) and the Theory of Reasoned Action. However, the conceptualisation of the PEN-3 model contrasts with some health behaviour-change models that focus predominantly on the individual perception of health (e.g. the theory of reasoned action, health belief model). Airhihenbuwa et al. (1995) emphasised that targeting all the three domains is particularly significant when redesigning health-intervention programs for culture and lay belief system. It leads to policy reformation in which health decisions are more likely influenced by a collectivist rather than an individualist perspective.

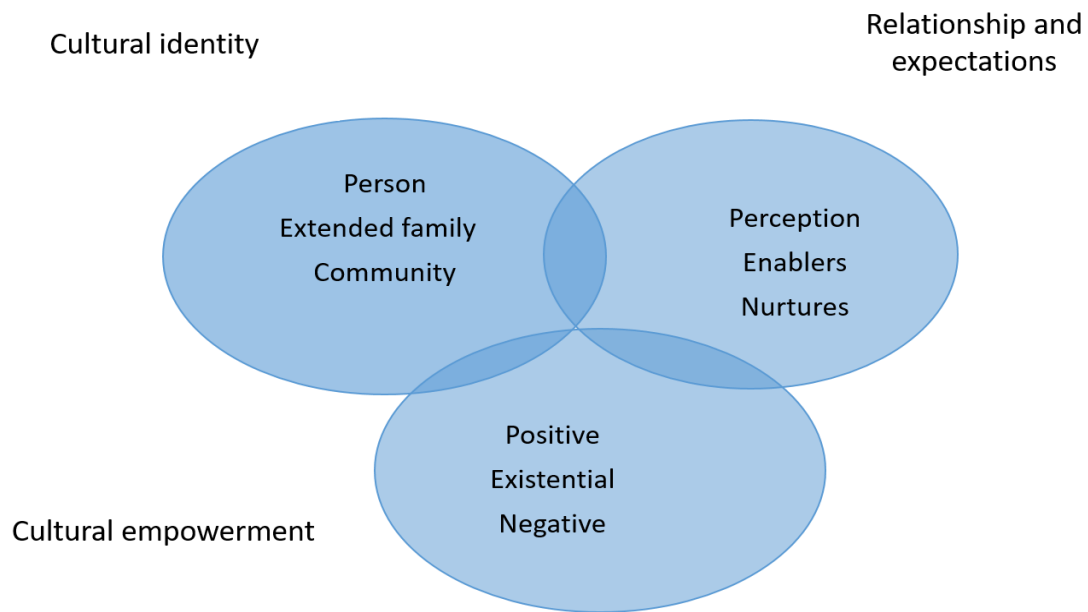


Figure 3.4. The PEN-3 Cultural Model (Source: Airhihenbuwa and Webster, 2004)

As identified in Figure 3.5, the elaboration of each domain of the model provides a rationale for the adequate consideration of the model in addressing cultural health behaviours. Cultural identity domain defines the target population, person, extended family, and neighbourhood. The "person" aspect focuses on the individual empowerment to consider healthy decisions. The "extended family" aspect concentrates on the whole spectrum of the family unit to obtain and understand healthy behaviour. The "neighbourhood" aspect refers to seeking community approval and acceptance of positive health behaviour and seeking assistance through community networks to change negative health behaviour to positive health behaviour. The relationships and expectation domain is used to assess the community perceptions, enablers, and nurturers that affect health behaviours, such as uptake of diabetes prevention programmes. 'Perceptions' include the knowledge, attitudes, values, and beliefs that either facilitate or inhibit health behaviours. 'Enablers' are the community and structural factors (for example, resources and accessibility) that facilitate behaviour. 'Nurturers' are reinforcing

factors, such as those from one's social and community network including family, friends and religious leaders. The third domain of cultural empowerment assesses the cultural appropriateness of health beliefs from the second domain and categorises these as 'positive' (focus on practices and supportive behaviours towards a person living with T2D rather than focusing only on stigmatizing behaviours), 'existential' (values and attributes that makes the culture unique and posing no threat to health treatment or diabetes self-management behaviours), or 'negative' (practices and behaviours that contribute to unhealthy behaviours) (Airhihenbuwa, 1995).

The PEN-3 Model has been applied as the conceptual framework of the policy agenda for various health issues, such as HIV/AIDS in the African population (Airhihenbuwa et al., 2009; Iwelunmor et al., 2014). A similar study by Abernethy et al. (2005) also examined factors related to prostate cancer screenings of African American men using the model. The PEN-3 Model also has been in a breast cancer screening promotion with Hawaiian and African American women (Ka'opua, 2008; Sheppard et al., 2010). The goal of this study was to assess the role of culture on behavioural factors that influence the way Black Africans self-manage their diabetes. Therefore, of particular interest to this study is the use of cultural identity and cultural empowerment domain of the PEN-3 model to explain the significance of cultural and lay belief system on diabetes intervention and health behaviours. This study adopts the principle of the PEN-3 Model central to cultural competence intervention to address health problems and construct their solutions within an identified population. This model could enable HCPs to tailor their education and prevention programmes to fit specific demands of the Black African communities. Thus, the PEN-3 model has the potential to be used by/with the communities to help them assert power and be more involved for themselves and be listened to effectively by the healthcare practitioners.

3.7. Observed research gaps

The policies reviewed were found to lack cultural sensitivity, despite acknowledgement in the previous literature of its importance in health intervention among the Black African population. This was in terms of disease knowledge, acceptability and accessibility of health care services, gender differences, use of other health practices and individuals' religious beliefs. Robust research that supports the effectiveness of a cultural approach when implemented in diabetes policy would promote person-centred care in addition to lifestyle and self-management strategies.

Although cultural tailoring may not go far enough to enhance acceptability and accessibility to health care services, it addresses and tackles diabetes prevalence's 'surface' structure. This could also increase acceptability of policy by making appropriate behavioural changes and involving the target group in the intervention design process and implementation (Renisow et al. 1999). According to Netto et al. (2010), the conceptual basis for health intervention, including diabetes management, needs to match the needs of the target community. In other words, the intervention needs to be immersed in the culture of the people from inception, attending to the needs as expressed by members of the community, be inclusive and delivered through that community.

3.8. Summary

The shift in the description and pattern of T2D resulting from poor health outcomes and increased demand for lifestyle changes has consequently led to increased pressure on the NHS and government policies. The challenge to reduce health inequalities and to achieve positive health outcomes has also led to individual empowerment; as a paradigm shift from the conventional medical approach of diabetes management to recognising other contributing

factors to self-management. Although empowering people living with T2D through education are an essential part of long-term disease management, it has been challenging due to less focus on the social determinants of health.

In summary, these reviews highlight the need for cultural tailoring for accessing and accepting health information and advice and development of culturally sensitive policies. This should consider the most important cultural aspect of the target group such as religious beliefs, traditional food and diet, social engagement and perceptions of illness. The PEN-3 cultural model focuses on the impact of culture and beliefs on health actions, and proposes that public health and health promotion specialists should not focus only on the individual, but instead on the sociocultural context that nurtures an individual's health behaviour within the community and the wider context.

The balanced approach to treatment and management with the perception that preventing diabetes is all about modifying behaviours, empowering individuals for a healthier lifestyle and prevention of modifiable risk factors should be made essential to help reduce T2D prevalence among Black African populations. Other influencing factors like social, cultural and environment should also be considered as contributing factors to the rise in diabetes prevalence among Black African populations. This should be better reflected in policies on diabetes management among high-risk ethnic minority groups to enhance self-care, competence and quality of life.

CHAPTER 4

RESEARCH METHODOLOGY AND DESIGN

4.1. Introduction

The critical review of the relevant literature provides the theoretical foundations and in-depth understanding of the research focus and identifies research gaps about the influence of culture and beliefs on how people from the BsSA community manage their diabetes. Furthermore, the methodology chapter describes how an appropriate research design of the study was developed in line with the research objectives. It also shows under what circumstance the empirical data underlying this thesis has been produced and analysed to answer the research questions, identify the researcher's biases and assumptions.

This chapter describes the methodological approach and design used to achieve the research objectives. This qualitative research explores the views and experiences on the role of culture and beliefs on diabetes self-management among Black sub-Saharan Africans (BsSA) with T2D. This is done through face-to-face interviews, which were then followed by interviews with HCPs and policymakers to explore further the themes identified in the semi-structured interviews. This chapter discusses the rationale for the qualitative research design, the ontological and epistemological frameworks, and how they influence the research paradigm underpinning the research study. The methods adopted for data collection and sampling process was also discussed. The chapter is divided into subsections: Introduction, research methodology (philosophy, approaches, and strategies adopted for the research), research methods, sampling methods, data collection and research instruments, data presentation and data analysis. It also addresses the ethical considerations and issues, limitation and bias, the

concept of reliability and validity of the research findings. It then presents the barriers and problems encountered during the conduct of the study.

4.2. Rationale for Research Design

The research design is a functional plan that focuses on all the steps in the process of achieving the objectives of a research project (Bryman and Bell, 2015). Thus, it provides the researcher with a clear research framework and guides the methods used, decisions, type of analysis and interpretation of the data. The classification of the research purpose or rationale often describes research methods in different features to provide evidence in social research (Saunders et al., 2009). These features exist in threefold; these are exploratory, descriptive and explanatory.

4.2.1. Exploratory Research

Collis and Hussey (2014) described exploratory research as a study that investigates phenomena or problem where there is little or no earlier information about the issue or problem. This is with a view of gaining insight, finding patterns or developing the proposition, rather than testing them. Exploratory research captures and describes the findings and interpretation of a social phenomenon of a situation or intervention process as experienced and understood by participants, by asking questions and assessing the phenomena in a new context (Ritchie et al., 2014; Saunders et al., 2015). Collis and Hussey (2014) identified various techniques used in exploratory research, including case studies, observational studies, and historical analysis, which can provide both qualitative and quantitative data in social science research. Furthermore, exploratory studies have few limitations on the nature of activities used in the study or the type of data collected (Collis

and Hussey, 2014). The exploratory study assesses which existing theories or concepts can be applied to a problem or when a new one should be developed based on participants' impressions and perceptions about the phenomenon. As such, exploratory research rarely provides conclusive answers or solutions to a problem but provides guidance if future research should be required. Although exploratory study generates qualitative information for future studies, the research process underpinning the study is flexible, and interpretation of such type of information is subject to bias due to the selection of methodologies that could best fit the research problem. This type of study usually makes use of a modest number of samples that may not adequately represent the target population.

4.2.2. Descriptive research

Collis and Hussey (2014) state that descriptive research defines a phenomenon by identifying and obtaining information on the characteristics of a relevant problem or issue, as they exist, or by exploring the possible correlation between two or more variables. This type of research aims at gathering information about existing information or situation about a phenomenon; either to test a hypothesis or to answer questions concerning the status of the subject studied. The descriptive research aims to describe characteristics or behaviours, so it often asks research questions that start with 'who', 'what', 'where' and 'how'. However, a descriptive study cannot conclusively ascertain answers to 'why'. Saunders et al. (2009) noted that it is essential to understand the phenomenon on which a researcher wishes to collect data and refine research questions and objectives before the start of the study. Descriptive designs can be retrospective or prospective. However, the descriptive design relies on both quantitative and qualitative research to organise information because it varies with the method of answering a research question. Therefore, it has been criticised for making the researcher

unable to control variables and report descriptive findings for one group of subjects; rather than comparing findings from different groups (Creswell, 2014).

4.2.3. Explanatory research

Explanatory research is the continuity of descriptive research (Collis and Hussey, 2014). Wyk (2012) refers to this type of research as an analytical study. Explanatory research establishes the causal relationship between variables and emphasises examining a research problem or situation to explain further the relationship between the variables or factors that affect the problem (Saunders et al., 2009). The researcher goes beyond describing the characteristics, to analysing and explaining the ‘why’ and ‘how’ questions about the occurrence of the phenomena being studied (Collis and Hussey, 2014). Explanatory design identifies and control variables in the research process, to allow a better explanation of the variables or the causal relations between the features of the phenomena studied. (Collis and Hussey, 2014). However, explanatory research is very structured in nature compared to exploratory studies.

Therefore, considering the correlation of the research questions of this study with the research objectives, this research adopts an exploratory research approach as it attempts to gain insights and interpretations of the situation from the participants’ perspectives. While other rationales such as descriptive and explanatory were considered, an exploratory study is adopted for this study to gain a deeper understanding, perspective and interpretation of culture and health beliefs as it relates to how BsSA communities self-manage their diabetes. Acknowledging the voice and views of this group has the potential to understand the issues faced by the community. Furthermore, it will provide new knowledge through a deeper understanding of the theoretical underpinning of the public health challenges of diabetes self-management among the BsSA community in the UK.

4.3. Developing research methodology

According to Collis and Hussey (2014), a methodology can be defined as an ‘*approach to the processes of a research encompassing the body of a research method*’ Bryman and Bell (2015) noted that researchers often confuse the terms ‘*methodology*’ and ‘*methods*’ in the context of a research process. The methodology is the detailed philosophical approach and concepts of the research process, comprising the epistemological point of view, whether qualitative or quantitative and the theoretical underpinning the methods of data collection, data analysis and interpretation (Jones, 2007; Bryman and Bell, 2015). On the other hand, methods refer to the ways and techniques of collecting data (Jones, 2007; Bryman and Bell, 2015).

It is paramount to recognise and understand the research philosophies, approaches, techniques and procedures to ensure the validity and reliability of the study. This also includes data collection and analysis (Saunders et al., 2009). This research process adopts the model ‘Research Onion’ as a logical and systematic approach required for gathering the necessary data for answering the research questions (Saunders et al., 2009). The research onion for this study is illustrated diagrammatically in figure 4.1 below:



Figure 4.1. Research Onion (Source: Adapted from Saunders et al., 2009)

4.3.1. Philosophical perspective for the research design

This section aims to discuss the philosophical perspectives underpinning this research and rationalises the methodological approaches of the qualitative approaches used in the study. Understanding the philosophical basis for the research and the position of a researcher helps to recognise the way people understand and explain what they know, which is considered very critical in the process of developing and designing research (Fisher, 2007; Saunders et al., 2009). Collis and Hussey (2014) argued that philosophy is a system that reflects the researcher's own beliefs and worldview on the fundamental nature of knowledge, reality and existence of the researched. Research philosophy can also be defined as a research paradigm, which is a broader framework that comprises the perception, beliefs and understanding of different theories and practices used to conduct research or develop knowledge (Collis and

Hussey, 2014; Saunders et al., 2015). A paradigm can be defined as a theoretical framework, which includes a system or lens through which people view a situation or grasp a subjective meaning of social action (Collis and Hussey, 2014). A paradigm includes the affirmed theories, approaches, beliefs, values, models, the frame of reference, methodologies and body of the study; and it could be a model or conceptual framework for observation and understanding of a phenomenon (Babbie, 2011; Creswell, 2014). A paradigm is thus a fundamental set of beliefs that guide a research activity. The justification of any research within the social sciences is based on three main elements of research paradigm, namely, the ontological and epistemological positions and methodological assumptions of the researcher (Easterby-Smith et al., 2008). Epistemology, ontology and methodology are interconnected and influence each other, and therefore each should be reflected upon when deciding on a research approach (Denzin, 1998). These standpoints shape research questions, objectives, methods and analysis and thus the knowledge produced from research. It reflects a researcher's own belief in the working assumptions of the social world, the approaches, interpretation and analysis of the research. This assertion confirms the reason why research should be carried out based on people's philosophical views and assumptions about the world.

4.3.1.1 Ontology

Ontology describes the philosophical study of the nature and forms of realities or being, conceptions of the realities and composition of the realities shaped through multiple socially constructed ideas by individuals (Saunders et al., 2015). It is a system of belief concerned with the assumptions and interpretation of what constitutes a fact and the question of existence apart from the specific objects and events (Ibid). The Ontology of research portrays two central perceptions of reality which includes how individual determines and construct realities through their experience and understanding of it (subjectivism), and how reality

exists independently from experiences and social actors (objectivism) (Saunders et al., 2015; Bryman, 2012). While objectivism refers to the actualisation of social entities that exist in realities external to and independent of social actors, subjectivism entails the conception of social phenomena through perception and indirect interactions with social actors (Saunders et al., 2015). Objectivist approach to this study would be merely concerned with diabetes as a clinical condition, ignoring the impact of subjective perceptions and experiences on the way the disease is being managed in practice. This research, therefore, takes the ontological path of subjectivism that describes how people's interpretations and understandings of a situation influence their actions or inactions.

Therefore, this study takes the ontological position that individuals with T2D experience and construct realities of self-management subjectively. It emphasises the view that people with T2D know and understand the reality of cultural values and health beliefs, which are accessible to their own lived experiences and interpretation of health, illness and healing. This ontological assumption explains how individuals create their reality based on the individual's experiences of life. This chosen research approach will offer the study participants an opportunity to challenge the researchers' assumptions about the reality and significance of the concepts, hence giving the research a robust overall design.

4.3.1.2 Epistemology

Epistemology explores the nature of knowledge, question ideas about culture and the ways of inquiring into the knowledge (Denzin and Lincoln, 2012). Epistemological assumption explains the forms and nature of realities in two different strands, namely, Positivism and Interpretivism (Creswell, 2014).

Positivism

The term positivism, which has its roots in a philosophical position known as naïve realism due to its logical empiricism and referred to as an Objectivist standpoint (Morgan and Smircich, 1980), states that the social world is the same as the physical world, which is an external entity (Easterby-Smith et al., 2008). Their ontological assumption is that reality is objective, measurable and external, and concrete structure, which affects everyone (Easterby-Smith et al., 2008; Collis and Hussey, 2014). Realities are measured through objective methods or experimentally in a precise and neutral manner. Blaikie (2007) and Bryman and Bell (2015) argued that a positivist epistemological position advocates the application of natural scientific procedures and techniques to study social reality from an empirical stance. This position is underpinned by the belief that reality is independent of the perspective of the researcher and the goal is to obtain experimentally theories that are universal and generalisable in their implications (Denzin and Lincoln, 2012; Collis and Hussey, 2014). Information developed can further be used in practice, though that is not the core purpose of the research. However, there has been the debate on the issue of whether the positivist paradigm is suitable for social science research (Silverman, 2011). Silverman (2011) argued that most quantitative social research does not fully conform to the simple form of positivism. Furthermore, Ormston et al. (2014) argued that the way the scientific investigation is carried out conflict with the reality of what innovative scientists do.

The central focus of this research focuses on is culture and health beliefs. Therefore, due to the underlying subtlety of meanings of self-management behaviours, the positivist paradigm will not support the achievement of this aim. The complexities of knowledge sharing and cultural practices, including beliefs, experiences and lifestyle, cannot be uncovered using a positivist approach. Although positivism acknowledges that issues such as misinterpretation

may arise, the approach is not able to explain the differences and complex lived experiences of the people. These debates raise the further question of whether the epistemological stance of positivism could answer the questions in social science research entirely. Thus, it is germane to this study.

Interpretivism

Interpretivism, also identified sometimes as phenomenology or social constructivism research refers to the way in which people make sense of their subjective reality and consciousness of the world around them. It, therefore, rejects the positivist view of objectivity that reality is independent of social actors (Bryman, 2012; Saunders et al., 2015). An interpretive approach embraces the fact that individual's reality, derived from perceptions of experiences modified by the society, differs from that of another person with the same objective reality (Fisher, 2009). Individuals' understanding of reality is not a simple account of 'what it is', but is rather based subjectively on the following:

- People's interpretation and understanding of reality, which is influenced by their values and their ways of seeing the world (lived and living experience)
- Understanding the world by directly experiencing the phenomena (the researcher is part of what is observed)
- Symbolic interaction, providing a means through which reality is constructed

Interpretivism is associated with the philosophical position of idealism and subjective in interpretation of knowledge (Morgan and Smircich, 1980). The ontological assumption is underpinned by the belief that there are multiple realities of the social world and subjectively constructed (Collis and Hussey, 2014); thus, people who are the subject, rather than the object (Easterby-Smith et al., 2008), determine realities. Interpretivism can also be closely

linked to social constructivism as it deals with the social action of an individual that can be either the actor or the researcher (Easterby-Smith et al., 2008). It is predicated on the fact that social strategies that differentiate the researcher, researched and objects of the natural sciences, are required to understand the subjective meaning of social actions. Interpretive philosophy contends that only through a subjective lens can the interpretation and intervention of reality be fully understood (Collis and Hussey, 2014). This epistemological position advocates the necessity for the researcher to understand the events, processes and culture from the perspectives of the participants, using qualitative techniques. Interpretive philosophy tends to explore and understand people's meaning and interpretation of ideas towards the same social phenomenon and leaves room for participants' contending or overlapping perspectives (Saunders et al. 2009; Collis and Hussey, 2014). Interpretivism allows the researcher to look deeper at the experience of individuals. Interpretive approaches allow adequate dialogue between researchers and the participants interviewed to collaboratively construct a meaningful reality of a phenomenon (Saunders et al. 2009). Description and analysis of data gathered advocates the understanding of political, social and cultural practices of the participants. These may be either relevant to existing theory or used as the basis of proposed theory or action. The meanings attributed to these factors are emergent from the research and data collection process. In other words, findings emerge through dialogue in which conflicting interpretation and perspectives are negotiated.

This research, therefore, adopts an interpretive philosophical stance due to the social and interpretative nature of primary research; predicated upon the view that there is a subjective meaning to the social and cultural actions of people and their environment (Bryman and Bell, 2015). This philosophical stance tailored towards the exploring the holistic understanding of how BsSA culture and health beliefs influence the way they self-manage T2D and their

responses to the intervention procedures. This paradigm is valuable for this research as it focuses on the social and cultural underpinning the reality constructed by the individuals studied (Fellows and Liu, 2008: 18). The research philosophy is selected to guide this research based on the relevance of the philosophy to answering the research question as well as achieving the research objectives.

The social constructivist epistemological framework was adopted for this research under the umbrella of Interpretivism due to the social and the interpretative nature of the research (Bryman, 2012; Creswell 2014). This framework is tailored primarily towards exploring the social factors that influence the lived experiences of people with T2D and the holistic understanding of perception and response to intervention procedures. It reflects the core values, ideals, and ways that BsSA community with T2D constructs their philosophies and behaviour around diabetes self-management through interaction with the social-cultural nature of the world around them and their health beliefs. Social constructivists view knowledge as constructed from the individual's experience as opposed to it being created external to them. Berger and Luckmann (1991) and Hammersley (1992) argued that truth or reality could be socially defined, based on the subjective experience of everyday life rather than the objective reality of the natural world. This shows subjectively, the people's philosophical views and perceptions about the world they live in and how they live in this world (Saunders et al., 2015). The framework investigates how BsSAs living with T2D create meanings, perception, and understanding of health, wellness and diabetes self-management. It will further investigate whether cultural values and health beliefs have a significant impact on how BsSAs with T2D construct their reality of self-management.

The social constructivist framework applies to this research as it primarily focuses on revealing how individual life, beliefs and linked health experiences became socially constructed and positioned within a particular cultural context. The emphasis on the participant's personal life experience and behaviour is central to this research as it helps to understand how the knowledge and realities of cultural values and health beliefs shape their health behaviour and outcomes. Investigating life experiences is a means of assessing how people with T2D create perceptions and understanding about their health. It further reveals the socially constructed factors influencing their health beliefs, attitudes, interaction and engagement with the services offered within the community.

Social constructivism advocates the application of critical observation of behaviours to avoid the classification of phenomena into a pre-determined form (Creswell, 2014). Therefore, to explore individuals' experiences and perceptions about the impacts of cultural values and health beliefs on diabetes self-management behaviour, it is important to have an in-depth study of the concepts and occurrences. Applied to this study, the examination of individuals' experiences will reveal the roles cultural values, and health beliefs play in T2D self-management among the BsSA community. Table 4.1 highlights the significant differences between Positivism and Interpretivism

Table 4.1. A summary of the key differences between Positivism and Interpretivism

	Positivism	Interpretivism
Method	Produces quantitative data	Produces qualitative data
Researcher	Independent of the study	Part of what is being observed

Data description	Specific and precise data, objective	Increases the general understanding of the situation, subjective
Research process	Hypotheses and deduction	Ideas induced from data gathered
Concepts	Data are operationalised to be measured	Data incorporates stakeholder's views and perspectives
Data Analysis	Reduced to simplest terms	May include the complexity of the whole situation
Generalisation	Statistical probability	Theoretical abstraction
Sampling	Large numbers selected randomly	Small numbers are chosen selectively for a particular reason
Accuracy	Reliability is high, and validity is little	Reliability is low, and validity is high

(Source: Collis and Hussey, 2014)

4.3.2. Research Approach

Saunders et al. (2009) posit that there are two main research approaches; inductive and deductive approaches. The deductive approach is mostly used in analysing existing theories or empirical testing of developed conceptual and theoretical structures deduced from general inferences (Collis and Hussey, 2014; Bryman and Bell, 2015). The deductive approach allows facts and evidence to be measured quantitatively and generalised based on the

selection of sufficient numerical sample size (Saunders et al. 2009). On the other hand, the inductive approach involves the development of theories from the observation of multiples of realities, where possible instances emerge from general inferences and data are collected qualitatively (Collis and Hussey, 2014). Saunders et al. (2009) noted that the inductive approach lays less emphasis on generalising results but on having a close understanding of the research context. The inductive method seeks to build theories through moving from individual observations to general statements and patterns (Saunders et al., 2009; Collis and Hussey, 2014). Blaikie (2010) noted that the inductive approach helps to answer the what, why and how research questions. Also, inductive approach is a more flexible structure that allows changes of research emphasis as the research progress, permitting the consciousness that the researcher is part of the research (Saunders et al., 2009). The inductive approach was therefore adopted for this study due to the interpretive nature of the research (Saunders et al., 2009) and the significance of detailed understanding of the research context and subject, requiring less need to generalise research findings. Inductive research is cumulative rather than generalisable. Each small-scale qualitative study does not seek to test the general theory, but to add to, and possibly amend accumulated knowledge by taking what is known as a new unique situation (Saunders et al., 2009). This research, therefore, adopts the inductive approach as it seeks to understand the meaning attributed to a culture and its impact on health outcome, rather than just testing existing theories and established research path in the public health field.

Nonetheless, it is important to refer to some potential risks that could exist with an inductive approach in research. One of the significant risks of this approach is that the emergence of valuable data and the selected theme is crucial, thus, if no useful data pattern is emerging, it could lead to anxiety (Saunders et al., 2009). The research questions were modelled with

great clarity to overcome this risk and ensure a successful research void of anxiety (Saunders et al., 2009).

4.3.3. Research Strategy – Ethnographic approach

It is important for the researcher to select the right strategy that would best answer the research question(s) whilst achieving the research objectives. This helps to establish whether a methodology conforms to a researcher's paradigm of positivism or interpretivism. Depending on the purpose of a study, various research strategies can be used for exploratory, descriptive and explanatory research (Blaikie, 2010). Some of these research strategies are suitable for a deductive approach while others are more appropriate for an inductive approach. However, none of these strategies is considered superior to any other as what matters is the ability to answer the research questions (Saunders et al., 2009; Collis and Hussey, 2014). These research strategies, including experiment, survey, case study, action research, grounded theory and ethnography research all have their advantages and disadvantages (Figure 4.2).

Table 4.2. Advantages and disadvantages of various research strategies (*Source: Collis and Hussey, 2014*)

Research strategies	Advantages	Disadvantages
Experiment	Identifies precise relationships between variables studied intensively using quantitative analytical techniques.	Limited knowledge of how recognised relationship exists in the real world due to oversimplification of the experimental situation.

Surveys	Allows researchers to obtain data about practices, situation or views of current relationships of variables through questionnaires or interview.	Lack of insights into the causes and processes involved in the phenomena measured
Case study	Capture and describe relationships that exist in detail.	Restricted to a single organisation or community and difficult to generalise findings.
Action research	Develops results or solution that is of practical value to participants and at the same time develop theoretical knowledge.	Restricted to a single organisation or community and difficult to generalise findings. Personal ethics are critical.
Grounded theory	Joint collection, coding, and analysis of data using a systematic set of procedures to develop a theory about a phenomenon	Researcher only collects data relevant to theories and ignore any other data to explain phenomena further
Ethnography	Socially acquired and shared knowledge to observe patterns of human activities and experiences.	Challenges with accessibility, trust and full participation as it takes research conducted over an extended period

4.3.3.1. Ethnographic Research Design

Ethnography is a research strategy that focuses on describing people and interpreting their behaviour and the social world in which they live through direct field study (Saunders et al.,

2009, pp 591). Ethnography is the intensive study of social interactions and naturally occurring behaviours of people or a cultural phenomenon and analysis of data collected in cultural contexts. It seeks to construct a detailed descriptive or interpretive account and holistic insights of people's view, beliefs, perspectives and practices of social life and cultural experiences of the participants of the study through detailed observations or informal and conversational interviews (Reeves et al., 2008). The use of ethnographic approach is the well-established methodology used increasingly widely in the social sciences and anthropological research. It is used to discuss extensively, gain clarification and probe emerging events or ask questions about unusual events or behaviours in a naturalistic manner of cultural or ethnic groups (Hammersley and Atkinson, 2007; Reeves et al., 2008). It describes the cultural experiences of a particular group of people and seeks direct engagement with their social and cultural world through participant observations as well as interviews (Hammersley and Atkinson, 2007). This anthropological root of ethnography rests on the perceived value and importance of discussions as participant's experiences and seeks to promote open flexibility to the changing places and spaces of social and cultural life, rather than instigating radically revised forms of ethnographic research (Forsey, 2010).

The definition of culture has changed over the years with the development of ethnography. Ethnographers explore culture in a broader context, including learning of ethnicity, religious activities, differences within the culture and languages of different communities (Fetterman, 2010). Ethnographers focus more closely on exploring distinct cultures within a border range of cultures or intercultural diversity (Fetterman, 2010). In contrast to scientific methods, ethnography is hardly experimental or analytical in aims. Rather, its rationale is inductive; building up a rounded description or lived experiences and identifying key issues emerging from the data (Flick, 2008). These emerging findings are used to emphasise the complexity of

multiple and often different perspectives and behaviours displayed in any social environment or cultural groups. The ethnographic study focuses on producing a detailed understanding of the circumstances of individuals studied intensively (Hammersley and Atkinson, 1995; Reeves et al., 2008). An ethnographer undertakes a study without prior hypotheses to avoid predetermining what is observed or what results emerge from the study (Bryman and Bell, 2015). The ethnographer explores and examines the hypotheses evolving from the study. The researcher has the opportunity of becoming immersed in the social or cultural attitude to collect naturalistic data in a realistic, evolving and reflexive way (naturally-occurring talk or real-world observation) rather than collating data under an experimental condition (Reeves et al., 2008). This qualitative study uses ethnographic design as a strategy to explain how culture and beliefs influence human health behaviours and lifestyle. It captures the individual's beliefs while eliciting a description and critical analysis of the behaviour patterns, beliefs and values of the people of a cultural setting. It also identifies the risks associated with diabetes self-management among the Black African communities.

In the research process, the ethnographic strategy is important to acquire an in-depth exploration and deep understanding of the research phenomenon from the participants' perspectives (Clark, 2006). This exploration can be done inductively through a survey of a small sample size undertaken in an inductive thematic manner (Reeves et al., 2008). The ethnographic study strategy is also suitable for a single study within relative periods, thereby providing a focus for in-depth research of phenomena in a wider social and cultural context (Collis and Hussey, 2014). This approach focuses more on the content of the experience and information provided by the people rather than quantifying the frequency of the specific information (Creswell, 2014). The researcher does not necessarily have to participate in the practices of the group but to investigate and understand the culture. Ethnography is concerned

with ‘learning about people by learning from people’ (Cruz and Higginbottom 2013). The study aims to investigate the different ways BsSAs sees diabetes self-management and interpret what is going on. Thus, as this qualitative study tries to research and infer the purpose and meaning of cultural and health beliefs on diabetes self-management behaviours among the BsSA communities, the ethnographic approach will be most useful for explaining why Black Africans in different situations and experiences take actions and options relating to diabetes care and self-management. Therefore, this research strategy was used to acquire the detailed understanding of the research aims and objectives (Saunders et al., 2015). Ethnography focuses on people’s culture and beliefs, and so it is a suitable strategy for understanding cultural influences on health behaviours. Fig 4.2 illustrates some of the steps carried out in the qualitative study using the ethnographic approach.

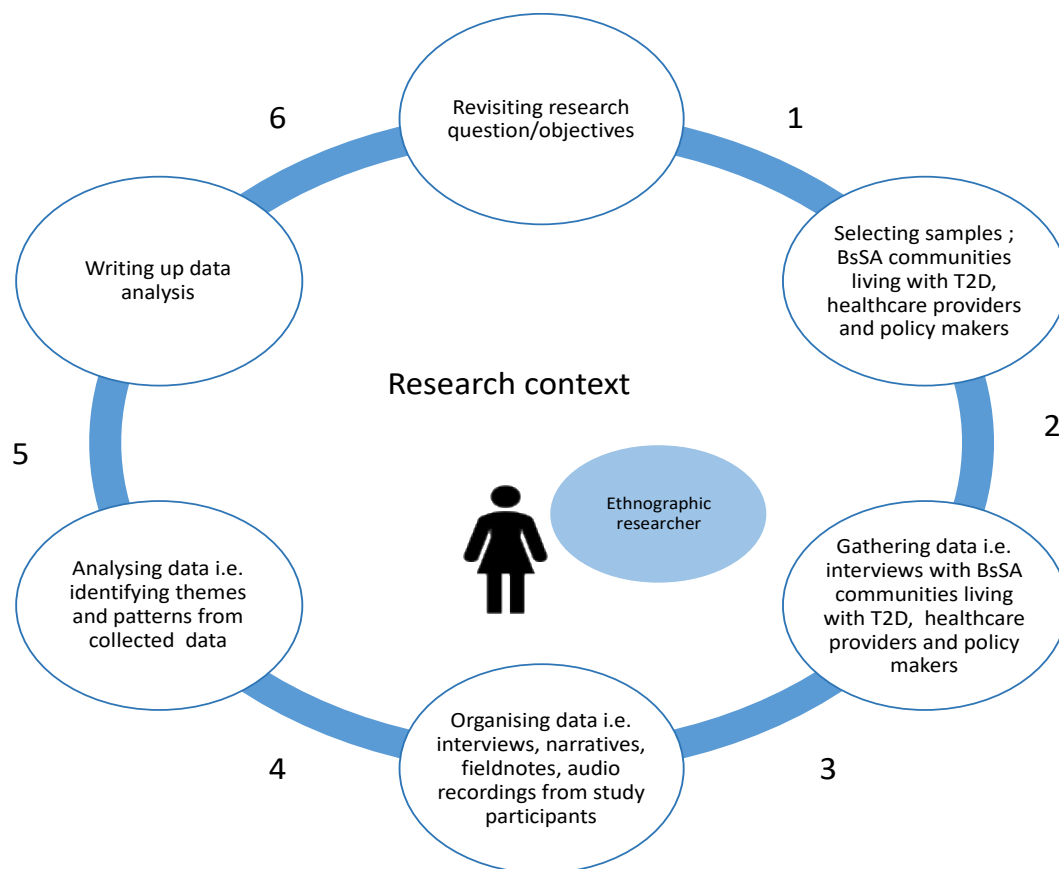


Figure 4.2. Ethnographic research cycle (Adapted from Rice-Lively 1994:33)

As illustrated in Figure 4.2, the ethnographic research cycle does not necessarily have to be one-directional because different points and actions can be revisited, for example, carrying further data collection.

However, the limitation of this strategy is that the determinations of this research on a minuscule sample size of people with T2D cannot be utilised for a general statement on people with T2D or a more encompassing setting. Nonetheless, it aims to provide a rich and in-depth understanding of the research context rather than generalising findings. As the data from the sample size is not necessarily meant to stand for the target population statistically, but to enable detailed exploration and holistic understanding of the research study, small size to ensure new evidence to interpret the phenomenon will be employed for the study (Ritchie et al., 2014). Detailed information is gathered through open-ended questions to provide direct quotations that can further identify the characteristics represented in the population.

The ethnography as a strategy in research has been criticised on various grounds for biases in the selection of data that fit into the study context. However, Reeves et al. (2008) suggest that ethnography can gather and construct empirical insights into social or cultural practices that are frequently obscured from public observation and generate solutions to research inquiries. Realising the ethnic influences on diabetes self-management behaviours among Black African communities, which has been identified to be one of the high-risk population, helps HCPs and policymakers to offer more dependable ways of creating awareness, improving treatment and services for this cultural group.

4.3.3.2. Navigating ethnographic positions as both insider and outsider researcher

The position of a researcher as an ethnographer in social science research in a qualitative study is highly debated. Researching a familiar environment using an ethnographic approach presents various advantages and methodological issues, particularly, if the researcher shares a common identity with the environment than an outsider. It is therefore important to examine researchers' awareness of any analytical interaction and reflexivity with the studied environment as a native researcher. The researcher may have varied perspectives and multiple identities as a native and an academic researcher for the study. Reflexivity asserts the researcher's consciousness of his or her relationship with the study, the observed situation around the findings and the researcher's influence and action upon it (Davies, 1999; Abdulrehman et al., 2016).

Therefore, it is imperative for native researchers that have multiple roles (insider and outsider) to consider the methodological issues associated with negotiating their perspectives on social-cultural factors and cultural knowledge in a research setting (Fetterman, 2010). Recognising the distinctive levels of knowledge and understanding that a native researcher exhibit of a familiar research setting, brings a unique contribution to the study both within and outside the field of study. It is imperative for a native researcher to be self-conscious of his or her positioning to the study in order to critically assess how various perceptions can be influenced by a diversity of influences and familiarities (Abdulrehman, 2017).

Recognising that native researchers conduct a study within a dynamic scope of insider and outsider reflexivity shows the complexity of the researcher's identity during the research process. Moreover, the ethnographer may need to make negotiations of perspectives that could shape the researcher-participant relationships and understanding of the ways of cultural

practices of the studied communities. Therefore, the researcher carefully focuses on individuals' lived experiences of diabetes self-management to infer the sociocultural aspects and belief systems that modify self-management behaviours in the communities. Interviews were relied comprehensively upon as the key source of information for the study. Thus, data were collected through an informal interview with people living with T2D, HCPs and policymakers. Equally important is observing participants in their homes, places of worship, cultural settings and cultural centres. This gave a contextual knowledge about the cultural ways and belief systems through which people from the BsSA communities describes diabetes and related challenges to self-management behaviours. Fetterman (2010) and Streubert and Carpenter (2011) suggested that native ethnographers immerse themselves in the field of study to gain an in-depth understanding of the studied phenomenon. Therefore, this researcher immersed herself in African cultural practices and social activities within the communities. Attending family and cultural events such as weddings, naming ceremonies, festivals and exhibitions, gave an in-depth understanding of how the society familiarises or does not familiarise with the cultural dietary and social needs of BsSA people with T2D. Hence, the native ethnographer's interpersonal skills and experiences with the community became essential tools during the research process (Fetterman, 2010). Although an outsider might not be able to understand the cultural motivations behind the participants' beliefs or actions, an insider's excessive familiarity with the studied community could also result to insensitivity to behaviours that appear "natural" and thus insignificant (Hammersley and Atkinson, 1995). Contextualising the emerging findings will avoid misrepresentation of the participant's meanings and purposes. Hence, it is important that ethnographic work conducted in health research should focus more on contextual components of the data.

4.3.3.3. Reflection as a researcher and native of a Black sub-Saharan African (BsSA) community

My initial concern as a native researcher, who is culturally rooted in a BsSA community, was that my awareness of the local culture and practices could make me neglect assessing views and behaviours that were naturally noticeable to me. Although the culture and practices of the community might be natural and familiar to me as a native of the community, it is naive for me to assume that the people will completely see me as an insider more than as an outsider. Therefore, it is important that the researcher becomes fully absorbed by the experience of the study participants in order to make sense of their lived experiences irrespective of positions of the researcher (Serrant-Green, 2002). For examples, when sensitive subjects came up during the discussion, such as the sexual effects of diabetes and family expectations as a female, and how I would have opted to treat an illness, I realised some of my questions and perceptions strike up against certain African culture and beliefs. In situations like these, when my African knowledge and academic role clashes, I submitted to my insights as a native of the community. This allows the researcher to gain trust and inclusive understanding of the complexity of the topic being discussed.

Having an 'insider' knowledge as a native researcher was valuable in the 'getting in' and 'fitting in' phases of this research study, however, unanticipated role ambiguity and moral challenges, could also arise as a result of this 'insider' knowledge and status. The dual positions could challenge the researcher's preconceived ideas and early decisions about the advantages and disadvantages of being an 'insider' or an 'outsider' in a familiar setting. (Burns et al., 2012). As a native of the studied community, I was aware of gender inequality among African cultures and the marginalisation of women's perspectives based on cultural norms and beliefs. I am aware that my identity as a Black African woman and a researcher could

simultaneously challenge or support my view and position within the research. I am also aware that the research participants might ask questions that might question my position as an African female researcher from the community. However, this prior knowledge helps my understanding of the complexity of choices and decision making among the study participants in relation to the subject studied. It also helps in reflecting on the significance of collective knowledge among families and the importance of considering this within the objectives of the research and prior to the collection of data in order to manage the interpretation of the data effectively.

Nonetheless, the distinctive contribution of the study was my ability to notice indigenous cultural gestures, speeches and attitude, such as the body language and inaudible signals of my study participants. For example, direct eye contact or interference during a conversation with an elderly African person is considered uncultured and disrespectful among the communities. Also, an inaudible signal, such as shoulder shrugs, can communicate as either a positive or negative response or a submission to a compromise. Understanding these non-verbal communications are essential for accurately assessing the open-mindedness and acceptance of the participant in the study. This allows the research to clearly understand when to change the subject of discussion to a more relaxed topic or when to re-phrase a sentence. However, I ensured all discussion was still within the scope of the research. Recognising the non-verbal communication with the participants allowed me to assess the lived experience of the BsSAs living with T2D and to holistically understand how they manage the disease in the comfort of their homes. Creating a relaxing and natural environment for the participants by communicating in a non-academic or non-professional language, avoiding the use of certain clinical terms, talking to some of them in their native dialect (Yoruba, Ibo, Pidgin English and Swahili), was beneficial for the study. This approach

allows a truthful and factual response from the participants. Although I do not understand some of the languages fully, I was able to greet and appreciate some of my participants in their languages. My understanding of the lived experiences of BsSAs living with T2D was based on listening to their personal stories and experiences shared about the difficulties of managing their illness. As a native of this community, I have an insider understanding of how people from the African community can be culturally immersed in certain practices and beliefs, which is important when disentangling the risks associated with T2D management.

Although I attempted to draw the boundary between myself as a researcher and my alternate identity as a native of the African community, it did not completely work for me. Besides, creating a professional gap in a cultural setting like the BsSA community would portray me as being insensitive and unrealistic. Building a rapport and relationship with the community members allowed participants to stay focused on the discussion, having the belief that they would have their health issues addressed through the study. This allowed me to enact both identities as a native of the community and as a researcher and be relaxed doing so during and after the interview.

As previously mentioned, (see 4.3.3.2), an insider position can either a benefit or challenge for a native researcher exploring a familiar community. Insider position in a study could facilitate easy access to the community and allow the researcher to emphasise the insider perspective on the study. However, familiarity with the cultural setting can distort research boundaries, which might affect the reliability of the study. Nonetheless, the benefits of an insider's position with a familiar cultural setting outweigh other professional dilemma when interacting with research participants at cultural or social events. Through examining the hypothetical eyes of my participants as an insider, I could infer that my age, gender and

position as a researcher could influence my identity and generate varying power differences between the participants and myself. These power differences could also impinge on the knowledge gained from the participants and the whole research process. Although nothing could be done to erase some of the power differences that characterise the BsSA communities, it was important that I am aware of my position while conducting the study so that I did not unconsciously compromise the situation.

Reflexive analysis of insider/outsider experiences revealed the middle ground which participant observers tend to navigate and the fluidity of the research process. Whilst insider knowledge and outsider status offered many advantages to the researcher, especially at studying a familiar setting and the level of knowledge of the subject under study, some of the inherent embodied, and socially constructed features of the researcher's identities and expectations raises the questions of consistency (Serrant-Green, 2002). Cultural competence in a familiar setting can be translated into role ambiguity, and at times, culturally entrenched role expectations of the researcher (Burns et al., 2012). Researchers, therefore, need to be aware of their positions within a study, the potential challenges navigating through those positions, the norms and possible ways of managing the crises that may arise from researching a familiar environment. Navigation of the position of a researcher as an insider and outsider and the significance of reflexivity of a native researcher is illustrated in figure 4.3 below.

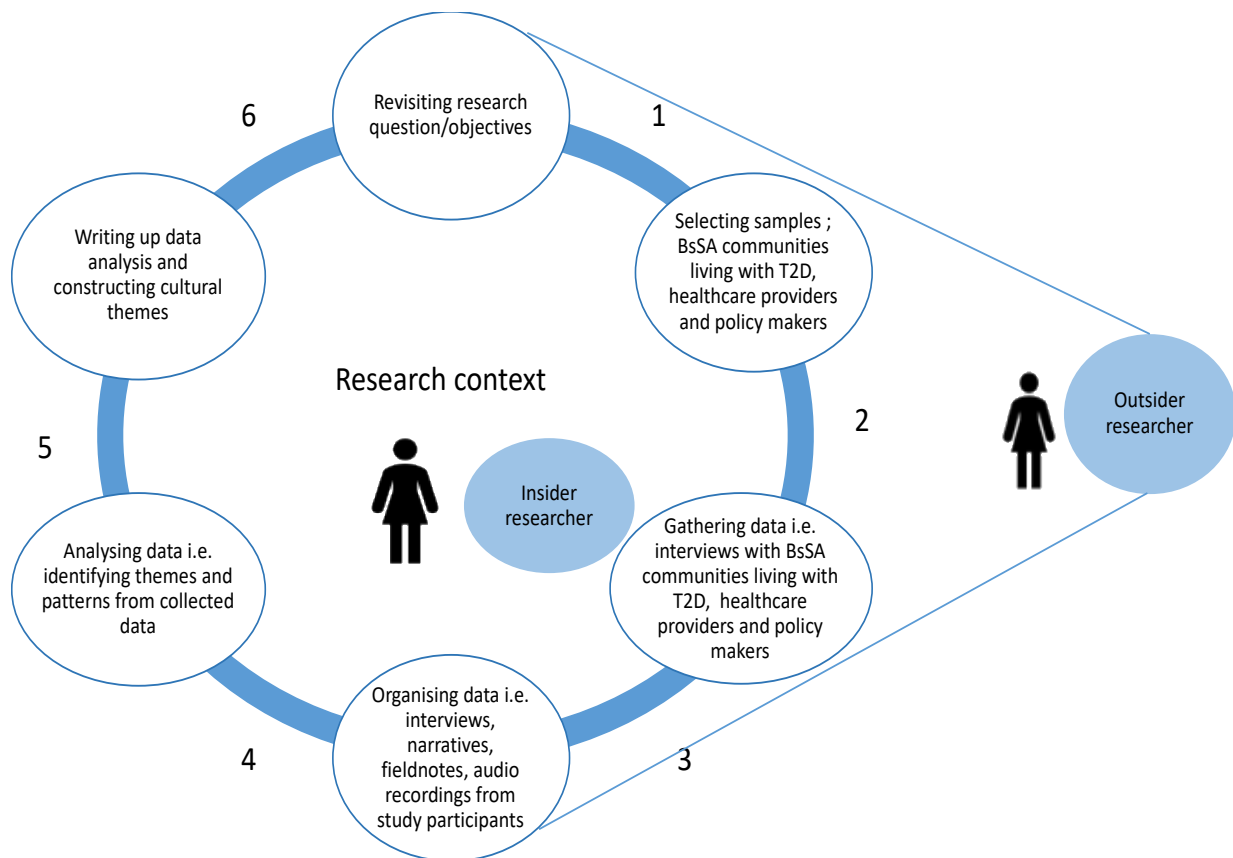


Figure 4.3. Ethnographer as an insider and outsider of a study (modified adaptation from Rice-Lively 1994:33)

4.4. Research methods

This study will be an ethnographic study with a focus on Black-African communities to help create an in-depth cultural understanding and interpretation of an aspect of health belief and behaviour to diabetes management issue assessed within the cultural group (Creswell, 2014). In this case, culture and health beliefs were addressed as an influential factor in T2D self-management.

4.4.1. Secondary Research

According to Blaikie (2010), secondary data are information that already exists in the process of conducting research. Nonetheless, the review of this information should be done in relevance to the research topic because it assists in validating the primary data gathered during the research; thereby providing more understanding of the research topic. The secondary data was used in the literature review of this study. The literature resources were reviewed to gather information to provide a conceptual framework in Chapters 2 and 3. These secondary resources include books, articles, journals, conference papers, documents and report, the archives, the government published statistics and professional journals (Hussey and Hussey, 2009).

4.4.2. Primary Research

A qualitative approach was chosen for the study as it helps to gather rich information and allows in-depth exploration of people's perceptions, behaviours and practices. It explores the underlying reasons that govern such behaviour, lifestyle and belief systems within the natural settings and the environment in which they take place (Denzin and Lincoln, 2012; Collis and Hussey, 2014). Qualitative research provides insight into a problem and allows the researcher to undertake and develop a dynamic and constructed reality or ideas by examining and investigating the lived experiences of the participants (Collis and Hussey, 2014). Unlike quantitative method that describes a problem and predicts the results, a qualitative approach instead explores the living experiences of the problem. This process helps to resolve the perpetuated problem of health inequality and lack of adherence to healthcare because it identifies the hidden lay beliefs and professional issues that will help HCPs and policymakers improve diabetes care by embracing cultural sensitivities to health behaviours and lifestyles.

The qualitative research asks questions about ‘how’ and ‘why’ practices take place and understanding the underlying explanation for such practice (Carson et al., 2001). Creswell (2014) emphasised that qualitative inquiry is most suitable for providing an in-depth exploration needed for an increased understanding of a phenomenon when researchers have limited knowledge about a particular problem. This exploratory research aims to critically examine the relationship between individuals and practices (Saunders et al., 2015). Therefore, this study enables the in-depth views of BsSAs living with T2D, HCPs and policymakers in relation to the overall strategies of improving health outcome and well-being within BsSA communities in their natural setting. The qualitative study will identify the impact and the importance of culture and health beliefs as an influencing factor for health and healing choices, food choices and diabetes self-management and provide insight into the views and beliefs held by the participants.

Creswell (2014) and Saunders et al. (2015) describe qualitative research as a way of explaining the meaning of living experiences for several individuals identifying shared and common values. This study will be focusing on individuals’ experiences and description of life situation, self-management behaviours and other diabetes-related issues. There will be a process of exploring socio-cultural settings around the health issue instead of testing the hypothesis about them, giving the researcher a subjective experience. Therefore, researchers explore participants’ views subjectively by immersing themselves in a natural setting of the participants (Creswell, 2014). However, since the sociocultural understanding of diabetes self-management behaviours among the Black African community is an under-studied area, a qualitative study will be suitable to establish the causal link with and between ambiguous health situations among this ethnic group (Saunders et al., 2015).

This research was conducted as a community-based study among the BsSA communities in Nottingham who have been diagnosed with T2D, HCPs such as General Practitioners (GPs) and nurses, and policymakers, which are the service providers and decision makers for public health intervention. The study will explore the understanding of how the subjects make sense of diabetes health care and treatments and how they conceptualise the impact of culture and health beliefs on diabetes self-care management. This research takes a subjective view of people's experience of life, giving an in-depth understanding of the situation being researched which can not only be observed (Silverman, 2013; O'Leary, 2014).

Exploring the patients' cultural and health beliefs and feelings about the disease and its management will give the opportunity to examine the significance of culture and health beliefs in intervention programmes on everyday life with diabetes. The research will be using an approach that will explore and assess the perception of the participants and explain how meanings translate to living experiences, values, choices and attitude to diabetes self-management. This methodology would allow discovering and accounting for experiences of people living with T2D. It also explains the meanings and perceptions of the experiences in the human stream of consciousness and perception. The study will also help to explore the cultural experience of the daily living of people with diabetes through interviews with the participants for the study. The focus on patients' response and interpretations would give the opportunity to see how patients create meaning to living with diabetes based on their culture and health beliefs.

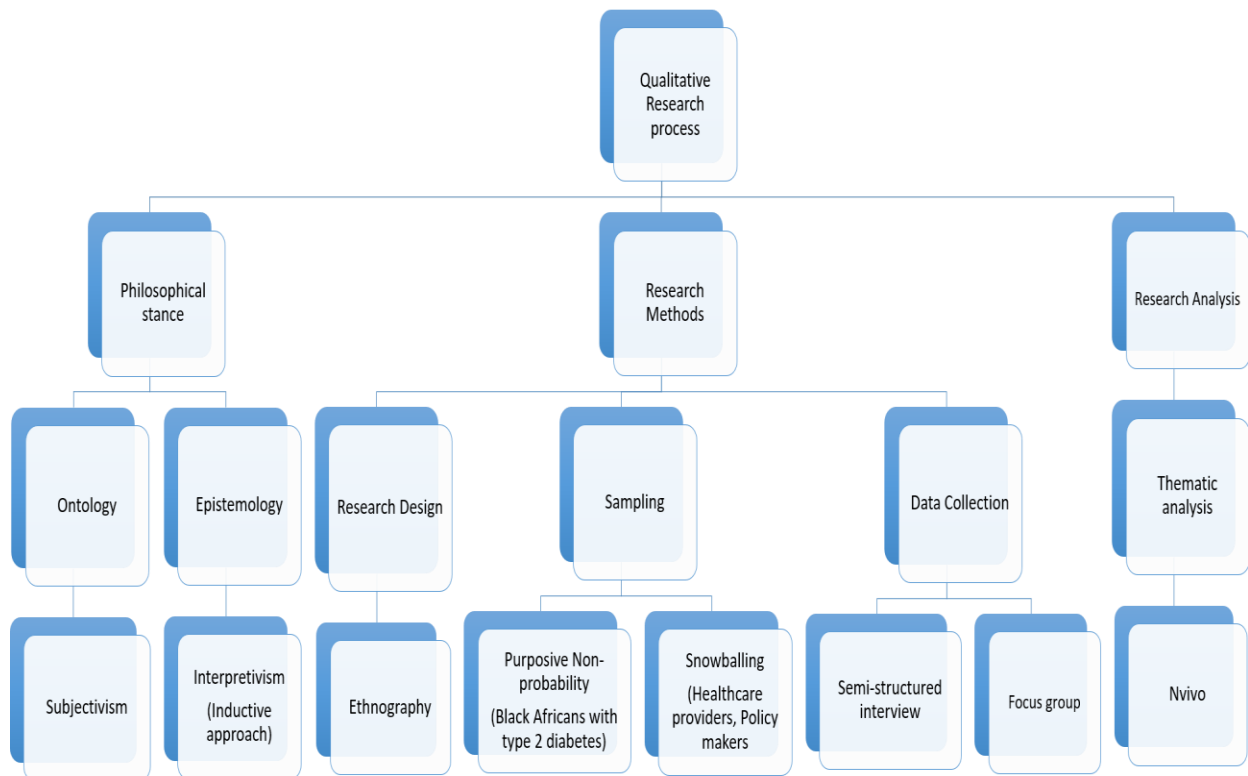


Figure 4.4. Schematic overview of the research process

Phases of the interview process

The interview process comprises of two phases of data collection (see Table 4.3)

Phase 1 Involved an in-depth semi-structured interview with Black Africans living with T2D and HCPs to explore the cultural context of diabetes self-management behaviours, and the data were analysed to provide contextual information to inform subsequent phase of the study.

28 in-depth qualitative, semi-structured interviews and 1 focus group were undertaken by Black Africans living with T2D and 10 HCPs from across the City of Nottingham alongside

with 6 policymakers from the across the local communities, its local statutory partners and the local voluntary and community sector.

Phase 2 involved in-depth qualitative research to explore the diabetes policy context, self-management strategies and HCPs and policymakers' engagement with the community. This identifies what has been done and what needs to be done differently to encourage increased cultural sensitivities in diabetes prevention and management interventions.

Table 4.3. Schematic diagram of the research method process

Process	Phase 1	Phase 2
Philosophical stand	Interpretivist	Interpretivist
Methodology	Qualitative (ethnography)	Qualitative
Methods	Focus group, face-to-face interviews	Face-to-face interview
Sampling	Purposive non-probability, snowballing	Snowballing
Focus of research questions	Identify the role and impact of cultural experiences and belief factors on diabetes self-management from the perspectives of Black Africans with T2D and HCPs who provide services	Identify the barriers and enabling factors to the reformation of diabetes policies and strategies from the perspectives of referring practitioners and further explore the previous findings and the influence of current

		diabetes policy
Participants	Black Africans with T2D, Healthcare practitioners (Doctors, Diabetes Specialists, Diabetes nurses, Dieticians)	Policymakers (Policy manager, policy officers, community manager (Diabetes education programme), health commissioning manager)
Location	Self-help and support groups, churches, mosques, diabetes education centres, families and friends	City councils, Voluntary Organisations
Sample sizes	28 Black Africans with T2D, 10 HCPs	6 Policymakers
Data Analysis	Thematic analysis	Thematic analysis

4.5. Sampling strategy for the study

4.5.1. Sample and Sampling Design

The criteria for the sample selection, as stated in the literature in previous chapters were because the role of cultural values and how they impact on health behaviour have not been researched extensively in the field of T2D health research among the BsSA communities. Therefore, I sought to interview Black African people with T2D who are willing to talk about their health and life experiences in relation to individual's cultural values and beliefs.

As discussed by Saunders et al. (2009: 212) '*the full set of cases from which a sample is taken is called population*', therefore, there was a need to select a research sample from a given population. In other words, a sample is a subset of a population (Collis and Hussey, 2014; Bryman and Bell, 2015). There are two major sampling strategies for social science research, namely, probability and non-probability sampling. Probability sampling is generally used for statistical or empirical research, elements in the population selected for research are chosen randomly, and each sample of the population has a known probability of selection (Bryman, 2012; Ritchie et al., 2014). There are different types of probability sampling, including random sampling, systematic random sampling, stratified random sampling and multistage sampling (Bryman, 2012; Ritchie et al., 2014). In contrast, non-probability sampling is used to select a sample for qualitative research (Ritchie et al., 2014). Ritchie et al. (2014) argued that units in non-probability sampling, are deliberately selected to reflect the features and characteristics of groups within the sampled study population. Qualitative research implies further that some samples of the population are more likely to be selected than others; hence, samples are not selected randomly. The accuracy and clarity of a qualitative study sample are interpreted by its ability to represent the salient characteristics and robustness of a population sampled (Ritchie et al., 2014).

There are three major non-probability sampling approaches in qualitative research, including purposive, convenience sampling and snowballing. Patton (2002) suggested that when using nonprobability-sampling techniques in a qualitative study, the choices of the target sample and size should be dependent on the research questions and objectives. This aids the collection of useful data and available resources for the study. Sample sizes are determined through "theoretical saturation" or "the point of data collection when new information no

longer bring extra insights to the research questions.” (Mason, 2010). The size of sample relies on the concept of theoretical saturation where the research interview continues until there is no further new information because only one ethnic group reflected upon for the research. Nonetheless, non-probability sampling has its limitation in that; the probability of each case chosen from the total population is unknown. It is therefore difficult to answer a research question that requires statistical representation of the population (Saunders et al., 2009).

The sampling of informants and subjects in the ethnographic study is often a combination of convenience sampling and snowball sampling (Bryman, 2012). Convenience sampling, which is non-probability based, refers to a sampling procedure in which the cases are selected due to their accessibility (Creswell, 2014; Ritchie et al., 2014; Bryman, 2012) and snowball sampling is a sampling procedure in which subsequent respondents are obtained from information provided by initial respondents. Therefore, a convenience nonprobability sampling approach was adopted for the people with T2D as a choice of target participants within the BsSA community. On the other hand, a snowball sampling approach was adopted for HCPs and policymakers as it was not easy to identify the members of the desired population that might be difficult to access (Bryman, 2012; Ritchie et al., 2014). As such, HCPs and policymakers were contacted through the previous contacts that were asked to help identify other members who meet the criteria for the study. This method of recruitment was important as it provided a means of recruiting “hidden populations” that may not be accessible through other methods of sampling and reduced the chances of using research participants from circles familiar to the researcher; thereby eluding a compromise that may affect the research outcome (Silverman, 2010). However, the limitation of this type of sampling is making initial contact and a bias selection of further contact.

4.5.2. Research setting and justification

The research took place in Nottingham City which has a population of about 325,300 and estimated to have more than 5% of the people living with T2D (Nottingham Insight, 2016). Many BsSA communities live in this city; therefore, the study was carried out in areas mainly inhabited by individuals from the BsSA communities in Nottingham. In Nottingham, the BsSA communities become visible through various community networks. Studies were conducted purposefully through community channels and community-based organisations such as self-help and support groups, churches, mosques, families and friends within local Black African communities.

4.5.3. Sampling Frame: Sample size

The aim of this qualitative research focuses on the exploration of sociocultural processes, as opposed to being representative of the larger population. Therefore, the qualitative sampling strategy identified a particular group that closely represents the social and cultural phenomenon been explored (Crouch and McKenzie, 2006). It is essential for the researcher to be immersed in the research field to be able to address the research problem and explore the social life and multiple realities of participants (Crouch and McKenzie, 2006). Therefore, a smaller sample was advantageous in allowing the researcher to get closer to participants to enhance in-depth enquiry of research context (Crouch and McKenzie, 2006). The size of sample relies basically on the concept of theoretical saturation where the research interview continues until no further new information can bring additional insights to the research questions (Mason, 2010) because only an ethnic group is measured and reflected upon for the research.

The subjects for the qualitative study were adults (Age range 35-75years) from the Black African community who are known to have T2D, HCPs and policymakers selected through community channels for a semi-structured interview. Age selection of people from the BsSA communities was based on the report that people from the Black African population are more at risk of diabetes at an earlier age (Diabetes UK, 2012a). Participants were recruited from voluntary organisations, support groups, local churches, mosques and self-help groups in Nottingham were approached for participation in the study. A total number of 48 participants were recruited for the research. Thirty-two Black African people diagnosed with T2D (Age range 35-75years), ten HCPs (Doctors, Nurses and Dieticians) and six policymakers (Decision and policy makers). People that were not willing to participate in the study were not included. The number of participants involved in the study was dependent on the attendance of people with T2D during the period of either their weekly or monthly meeting. Nevertheless, I will still be working towards achieving certain sample size, which implies that approximately 48 participants selected from the three samples will be interviewed for the research (O'Leary, 2014). The breakdown of participants is presented in the next chapter (Chapter 5) Table 5.1 and Table 5.2

4.5.4. Access to sample

The ability to gather primary data during the study was dependent on the access to the community and HCPs. However, the level at which the sources are relevant and appropriate for the research relies solely on the research questions, objectives and research design (Saunders et al., 2009). Identification of these communities and access to communicate with them was facilitated by the researcher's cultural identity as a Black African living in the city. With regards to accessing people with T2D, I am aware that recruiting through the NHS can be problematic and challenging due to the ethical issue, so I recruited from a local

organisation, self-help groups, religious groups within the community and community centres. The starting point was contacting the leaders and organisers of groups and centres to discuss proposed research to get contacts for participants. I contacted some friends of mine who currently work within African community health projects to explore the prospects of my research. They spoke with their colleagues working on diabetes projects on my behalf, some of which have further contacts with HCPs. Due to the non-intrusive nature of this research, there were no objections or limitations raised by link contacts and participants with regards to questions asked about the purpose of the study.

I am mindful that recruiting HCPs through the NHS can also be challenging. Therefore, they were recruited through local organisations, non-governmental agencies and community centre and the policymakers were recruited through government and health agencies. Effectively, therefore, I made contact contacts with health promotion agencies and community leaders to discuss the purpose of research, attending group meetings with support groups, religious groups, and self-help groups. I attended seminars and organised by BME (Black Minority Ethnic group), voluntary and community sectors for PLWD within Nottingham city in the East Midland region of the United Kingdom.

4.6. Data Collection Process

The use of data collection instruments for an in-depth understanding of an issue or knowledge in ethnographies can vary considerably even in projects with similar aims (Robson, 2002). This study focused more on in-depth understanding rather than breadth of the research. It is imperative for an ethnographer to present the description and interpretation of the findings from research work (Atkinson and Hammersley, 2007). This qualitative research incorporates the use of semi-structured interviews for data collection. The choices made for the data

collection instruments followed an extensive literature review of relevant studies on diabetes self-management among BME groups.

4.6.1. Pilot Testing

A pilot study was conducted at the beginning of the first phase of the data collection with four participants (i.e. two BsSAs living with T2D and two HCPs) prior the actual data collection to ensure unbiased questions, good management of time and refine the research instruments. This represents the first stage of the data collection process to test the data collection technique for adjustments on any of the interview sessions. The researcher to ensure comprehension of the questions by all study participants adjusted the highlighted obscurities in the study instrument. The tool developed for the interview was piloted before being used in the main phase of the study. The interview guides are stated in Appendices F, G and H.

Reflections on the pilot study revealed the following:

- Nervous moments for the researcher, being first sets of interviews conducted and this led to interviews not flowing as it could have, and time-consuming. However, the researcher was able to manage the situation effectively.
- Some of the questions needed reframing to get richer information from participants

Outcomes from the reflections were used as a guide to improve the skills, time management and reframing questions for subsequent interviews. In addition to using reflections from the pilot study to evaluate the effectiveness of the research design and data collection instruments, feedback from supervisors was taken into consideration.

4.6.2. Data collection and research instruments

Two main methods were eventually employed in the collection of data: semi-structured interviews and focus group. Participants' information sheets and flyers were created for the data collection to create an understanding of participation in the research, increasing the chances of the participants opening-up and supporting the study (see Appendices D and E). Also, informed consent for interviewees was not compulsorily signed but was confirmed verbally during the interviews thereby suiting the less formal nature of interactions (see Appendix C). The next section discusses in detail the data collection process.

Semi-structured interview

Interviews can be categorised into different patterns, namely, structured, semi-structured and unstructured interviews (Patton, 2002; Saunders et al., 2015). A structured interviewer administers questionnaires based on a standardised and predetermined set of questions with no variation between participants, and offered response are recorded on scheduled and pre-coded answers (*ibid*). However, semi-structured interview entails the interviewer putting down proposed themes as guidelines and questions to be covered during the interview session (*ibid*). The primary method for the data collection adopted for this qualitative study is semi-structured interview as it allows for the important aspect of structured and unstructured interviews to fuse together. The structured aspect of the interview approach helps the interviewer to gain a form of control and hence steer the interview in the preferred direction and prevent the interviewee from 'straying' off the important topics to be discussed. The unstructured aspect of this interview process allows the interviewer to effectively exhaust a given question or theme while allowing interesting issues to emerge from the discussion.

The semi-structured approach of collecting data was chosen for the study to explore and provide an insight into participants' perspectives of culture and health beliefs on diabetes self-management and to give an in-depth understanding of the meaning participants attached to the conventional system of diabetes management (Saunders et al., 2015). Individual semi-structured interviews are used in exploratory studies to ask questions that are open-ended, creating an opportunity for the participants to speak openly and unreservedly, and for the researcher to ask questions on the emerging content (Legard et al., 2006; Collis and Hussey, 2014). Therefore, by being inductive, semi-structured interviews have an affinity with this study's aim of capturing rich and strongly descriptive data from participants' perceptions, understanding and experience that cannot be directly observed (Creswell, 2014; (Braun and Clarke, 2013). Thus, looking forward to participants' perspectives and views, exploring the motives behind individuals' experiences, decision, attitude, beliefs and procedures towards diabetes self-management and new innovative ideas and suggestions. Data collected during the interview is aimed to address knowledge and treatment misconceptions gap between service users and service providers, comparing participants' views and how diabetes self-management is being interpreted individually. The problem of health debates meaning different things to different people, and more often, people with certain cultural values and health beliefs tend to show more individual perspectives of healthy living. A better understanding of the relationship between the contextual determinants of healthy behaviour and outcomes among people with T2D could facilitate the development and implementation of culturally sensitive interventions that could modify individuals' beliefs, assist acceptability and promote positive self-management behavioural changes among this population.

The use of open questions in this study allowed participants the chance to share their detailed experiences in their terms without restricting any opinion. It also enabled the researcher to

respond meaningfully and informally to what participants communicate (Bryman, 2012; O'Leary, 2014). Therefore, the use of semi-structured interviews is significant for this study as they facilitated a clear understanding and detailed exploration of the key themes and questions to identify various observable facts of the study (Saunders et al., 2009). This approach allowed the researcher to have further knowledge of hidden issues that may not be previously considered to answer the research questions, but significantly flexible for the research aims and objectives through a set of questions (Patton, 2002; Collis and Hussey, 2014).

The interviews were done in a relaxed manner. Though the questions were made flexible to allow for an in-depth understanding of the research context, the focus was still based on the topic guide and individual's experiences. Nevertheless, one of the disadvantages of this type of interview is that it could be time-consuming, not just in collecting the data but also in transcribing and analysing the information gathered. Besides, it is easy for the interviewee to digress from the focus of the study and this flexibility may lessen the reliability of the study.

Nevertheless, a general thematic framework derived from research questions was explored to provide a stance for the study. For this research, interview guides were developed and prepared for all three parts of the interviewees to ensure consistency in the interview process. These questions were written at the beginning of the study, but were later revised and properly drafted at each stage of the interviewing approach. One of the main reasons why researchers use interview guides is to ensure that important questions are not forgotten during the interview (see Appendices F, G and H for interview topic guides) as digressions or added subjects of discussion may occur in most interviews (Bryman, 2012). Also, Saunders et al. (2009) stated that the location of an interview might influence data collection. Therefore,

convenient time and location of the venue for an interview was arranged with participants before conducting the interview.

Focus group

A focus group, also known as a group interview, is a type of interview with a group of people usually facilitated by the researcher, who presents the topics to be discussed by the participants (Saunders et al., 2009). This research initially did not plan to use this method, but this happened coincidentally during one of the meetings with a support group. It happened as the people debated amongst themselves about good health seeking practices relating to specific cultural practices and how those influences health behaviours. A typical example was a discussion on the use of alternative self-management remedies and challenges with the current health systems' approaches to BME communities. The informality and friendliness amongst participants enhanced this process, as there were no perceived reservations on shared experiences. Information from the proceedings of this focus group was recorded as part of the interview, though; the information gathered was not presented in the findings, as there were repetitions of words during the individual interview. Nonetheless, the researcher was granted permission to audio-record and make notes in front of the participants because confidentiality had been assured before the start of the discussion.

4.6.3. The interview procedure

All interviews lasted between 45 and 90 minutes with open-ended questions to aid discussion with the participants. Each of the participants was given enough time to express personal thoughts and experiences about their diabetes. To ensure that the responses were recorded, a digital voice recorder was used to record the answers of the participants. The interviews were audio-recorded with permission from the participants, and the results were later transcribed

verbatim into textual format manually to a personal and password-secured laptop. All the interviews took place in arranged location as agreed with participants. The time and date for the interview were scheduled at the convenience of each participant (Naden and Saeteren, 2006). Some of the participants were interviewed at their private homes to preserve confidentiality while others were carried out in arranged public location, depending on their preferences. This data collection technique provided the opportunity to observe that participants prefer to share the experience in the comfort of their homes, especially when they were enjoying and sharing the values of their cultural food preferences and beliefs. This data collection method provided the opportunity to watch participants and make notes in their lounge where they privately had their meals during lunch break. Field notes were prepared immediately after the completion of each interview, and a reflective diary was kept to help during analysis. Interviews ended when the participants had no further information to share with the researcher. A copy of the information sheet, consent form and interview schedule and the contact details of the researcher was provided to each interviewee for possible future enquiries (see Appendices C, D, F, G and H)

4.6.4. Access issues

Diabetes management as a significant public health issue, which requires reflective debates, especially among the ethnic minority groups in the UK, belies the actual complexity of accessing the people with T2D and the service providers, especially from the NHS. Field access can be problematic for qualitative researchers (Flick, 2008), particularly research related to health issues. Recruiting process through the NHS is the subject of a strict ethical clearance before any form of recruiting of the patients and staff. Therefore, participants were recruited based on informal discussion through community channels, such as churches, mosques, families and friends, self-help and support groups.

The practical effects of the problems with accessing the participants are somewhat evident. Firstly, it can be difficult to recruit Black Africans with T2D who do not actively participate in local and community activities like support and self-help groups. They could, therefore, be mainly contacted through churches, faith groups, families and friends. Secondly, HCPs that decline to participate may be those with the understanding of the complexities of the phenomenon within the health care system in the UK. This might indeed induce a bias selection of samples whereby a participant is selected into or out of the sample. Such a situation and observation will be discussed when analysing the results to understand the reasons behind the active involvement of participants in the study.

4.6.5. Fieldwork reflection

At the time of this writing, many of the participants recruited have been interviewed in their homes. This approach reflects the trend whereby people feel more relaxed to share their experiences in the comfort of their home. Only one of the HCPs requested to have the interview in the office for privacy, as they did not want family members to be involved in the discussion. Many of the participants from the Black African community feel it is a real opportunity to have a voice to share their experiences and actively participate in a study that can improve the service provided for people with T2D. Participants have also stated that they see the interview session as useful opportunities for them to reflect on their lifestyle and diabetes and other illness management.

The participants' reflection on the interview process and my research interest has been valuable in addressing my role as a researcher in this study. That this research project has affected the participants, through giving them a voice, is undeniable. However, as this is a

health-related study, my influence on the participants as a Black African is contained and negotiated to avoid compromising the internal validity of the data collected.

4.6.6. Feedback from academics and professionals

Presentation of the research at school seminars and conferences, national and international conferences with feedback ensured that the research stayed focused and improved in quality (see Appendix K). In relation to the sociocultural context of this study, this research has produced two peer-reviewed academic papers accepted for publication (see Appendix K). Papers presented in International Sociological Association (ISA) and the British Sociological Association (BSA) were followed by presentations to peers of as well as academics with extensive knowledge in the field of Public Health and Social Science Research. Challenging questions and constructive feedback from the academics and professionals have immensely improved the quality of this thesis.

Questions, comments and shared personal experiences with other academics in the discipline shed further light on health behaviour and practices. Consequently, their views and opinions were further incorporated into the analysis of the collected data.

4.7. Data Management, Processing and Analysis:

4.7.1. Transcribing interview data

Data transcription is often seen as an important phase of qualitative research, particularly when data collection is made using the interview method (Flick, 2014). Data transcription appears to be an easy, practical task. However, Bailey (2008) argued that the process of transcription requires reduction, data interpretation, and data representation to ensure the

transcript produced is readable, meaningful and significant. Hence, data transcription is not an easy task; it requires time, full attention and concentration to understand the conversation and reflect on the situation and non-verbal responses. The researcher transcribed the recorded interviews to ensure their accurateness and interpretation (See Appendix I). Each audio-recorded interview was compared with each other and reflective diary notes kept by the researcher to ensure an accurate reflection of the responses. As explained to the research participants, handling of the collected data (such as interviewee details, interview recordings and field notes) would be carried out with confidentiality. Anonymity was also of utmost importance to protect the participants' identities in the study. All the transcripts were given unique codes and numbers for easy identification.

4.7.2. Data Analysis

Analysing qualitative data involves a range of processes whereby the researcher moves from qualitative data collection to making sense of the vast amount of information, and then explaining and interpreting the views of people and situation studied (Creswell, 2014). The interplay between a researcher and the collected data is what is referred to as data analysis (Strauss and Corbin, 1998; Saunders et al., 2009). The researcher undertook following the data collection, verbatim transcription of the interviews (see Appendix I). The process revealed respondents' attitudes through their responses and conversations during the interview. Also, all field notes from observations and spontaneous focus groups were written out and compiled to synthesise and make sense of the collated data for simplicity during the analysis phase. As explained to the research participants, handling of the collected data (such as interviewee details, interview recordings and field notes) would be carried out with confidentiality and anonymity to protect their identities (see Appendix D). Analysis of the qualitative data was conducted in two themes: the first themes developed from the literature

review and the second themes that emerged from the interviews. There are several ways of analysing qualitative data, namely: narrative analysis, discourse analysis, content analysis, ethnographic analysis, thematic analysis and conversation analysis (Silverman, 2011; Creswell, 2014). The analysis strategy went through a series of iterations before thematic analysis was found to be the most appropriate method to address the research questions in the given timeframe.

4.7.2.1. Thematic analysis

A thematic analysis was adopted for the study to give the researcher a broader view of the topics discussed so that emerging patterns could be drawn out from the research data (Creswell, 2014). The thematic analysis uses patterns across data sets that are relevant to the research in addressing research aims and answering research questions (Braun and Clarke, 2013). Therefore, the data analysis adopted in this study was thematic data analysis procedure to ensure that a rich account is derived from the interview (see Appendix I). For example, in this research, findings on participants' activities from interviews and observations explain how the informal cultural practices and beliefs about T2D influence how studied participants' self-manage the disease and make health decisions. While individual discussions were analysed, specific emphasis was also placed on the attitudes and responses of the individuals as these determine the different definition of cultures. This method of analysis also offers flexibility to the researcher and research participants in determining themes constituting the final output of the study while maintaining consistency throughout the analysis (Boyatzis, 2012; Braun and Clarke 2013). Although there are other ways of analysing qualitative data, for example, content analysis, discourse analysis, grounded theory and narrative analysis, they were not seen as suitable for the purpose of this study. Content analysis categorises the verbal and behavioural interpretation of the data, while discourse analysis, focus on how

languages and spoken interactions are used to construct meanings to the social world (Silverman, 2011). Grounded theory formulates a general statement or theory about a phenomenon or a population by comparing different cases, while narrative analysis reformulates stories narrated by people in different contexts and established them on their experiences (Braun and Clarke 2013). However, the thematic analysis explores and explain the concepts and meanings associated with the lived experiences of participants by exploring the role of cultural belief systems on both prior and emerging issues (Creswell, 2014).

As the primary data collected for this study were a set of interview transcripts, the analysis approaches taken needed to be suitable for this type of data. According to Creswell (2014), qualitative thematic analysis involves three main stages. The first phase involves organising and preparing the data collected into a textual and written format (verbatim transcription). The second phase comprises of a systematic phase of “reducing the data into themes” (Creswell, 2014). The second stage develops preliminary descriptive and interpretive classifications using evidence from the transcripts, the literature review and the theory or conceptual framework underlying the research. In the third stage, these preliminary codes are examined to identify connections and develop pattern codes, while in the fourth, clusters of the respondents' comments and the researcher's notes are reviewed to arrive at underlying themes. The final phase demonstrates the identified, coded data that are emerging across the various transcribed interviews and form the basis for writing up the data (see figure 4.5).

One of the main advantages of thematic analysis, as mentioned earlier, is the flexibility that it offers researchers in conducting exploratory research (Creswell, 2014). It allows researchers to draw out patterns and themes even after initial themes have already been identified from the data (Ritchie et al., 2014). The researcher used qualitative thematic

analysis to describe and interpret the emerging themes of the data transcripts by using a systematic approach to code common patterns and themes. Therefore, the analysis began with the initial coding of prominent words, phrases and sentences, where the data were later condensed and organised into meaningful categories. These emerging themes and categories were coded and compared to identify similarities and differences. Emerging themes and categories were focused on the identified factors in the conceptual framework of the study.

The audio recording and the open-ended questions used in the interview allowed the researcher to become familiar with the data, and code responses with single words or phrases that explained each of the groupings. Saldana (2009) defined codes as words, ideas, or phrases that describe units of meaning. Coding was used to summarise, combine, and sort the observations made from the data into themes and categories to facilitate analysis (Gibbs, 2007; Flick, 2014). The data collected was arranged manually and coded in tables, grouped, examined, and classified for consistency. Examination of interview transcripts, field notes, and the literature review helped in analysing the results. Data were analysed to discover general trends, and the demographic questions provided information about the characteristics of the participants interviewed. Common themes emerged and weaved into the summary findings. Some of the emerging themes identified were cultural beliefs and knowledge about T2D, self-monitoring behaviours, cultural values of traditional medicines and diabetes care transformation initiatives through community networks (see chapter 5 and 6 for comprehensive discussions). This technique involved checking data for external diversity or the extent to which the various categories differed from each other (Patton, 2002). An overview of the analysis process is seen in Figure 4.5 below.

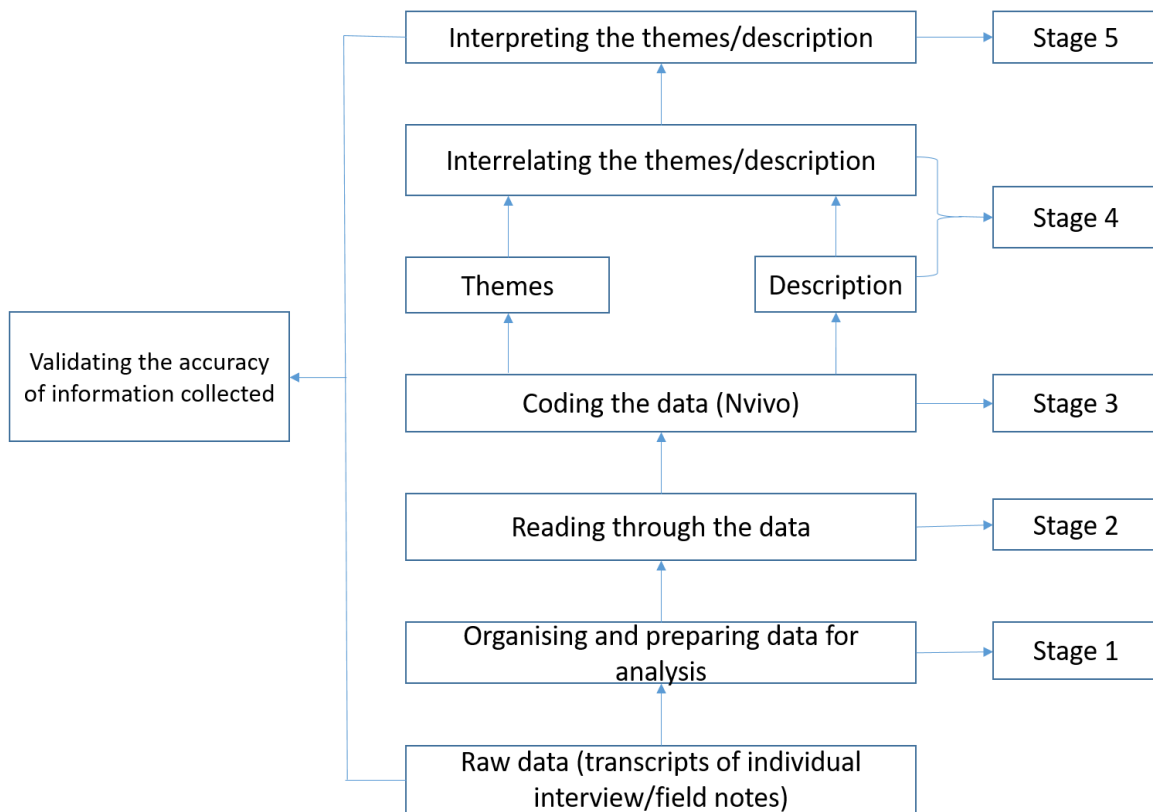


Figure 4.5. The process data analysis (Source: Creswell, 2014)

4.7.2.2. Use of QSR Nvivo 11

The use of software to facilitate research analysis has become an important aspect of analysing qualitative research. Miles and Huberman (1994) noted ‘the researcher who does not use the software beyond a word processor will be hampered in comparison to those who do.’ (Miles and Huberman, 1994: 43-44). Historically, qualitative researcher code and analyse their data manually. However, there has been a shift in recent times as more researchers are leaning towards the use of software (King, 2008). Some of the main CAQDAS packages available today include MAXQDA 12, ATLAS.ti, Hyper RESEARCH and QSR Nvivo.

Creswell (2014) recommended using electronic data control for qualitative data analysis. Upon careful evaluation of the different software, QSR Nvivo version 11 was chosen for the

research due to its availability and user-friendliness (see Appendix J). This software helps to facilitate data management, assist coding process and derivation of the key patterns and themes. The software provided storage and organisation of data in codes to compare the data collected including interview transcripts, observation notes, personal comments, relevant literature, personal reflections and other computer-based documents pertinent to the study. It assisted in tracking the processes involved in the whole research journey, thereby ensuring transparency. The data was organised into themes to provide emerging patterns from interview results to improve reliability and validity (Saunders, et al. 2015; Patton, 2015). Data gathered was analysed and reflected upon to understand the various challenges faced during the collection of data and how these problems were resolved for the study. Data analysis co-occurred with the data collection, and this will continue as a process throughout the time of the research study. Memos, which represent the additional background notes, and information that focused on crucial issues, emerging codes, and interconnections were kept during and after each interview.

4.7.2.3. Presentation of participants' results

The findings presented in this study are drawn from in-depth interviews with BsSAs living with T2D, in-depth interviews with HCPs and interviews with policy and decision makers. Triangulation of the findings from these sources (see figure 4.6) was simultaneously analysed and associated quotes from these sources. The unique codes and numbers used for participants' references are presented in Table 4.4, 4.5 and 4.6.

Table 4.4. Special identification codes for BsSAs living with T2D

Participant (codes)	Gender	Age (years)	Treatment	Religion	Marital status
BALWD#1	Female	48	D,OM and A	Muslim	Married
BALWD#2	Female	53	D, OM AND A	Christian	Married
BALWD#3	Female	42	D and OM	Christian	Married
BALWD#4	Female	52	D	Christian	Divorced
BALWD#5	Female	52	Insulin, D and OM	Christian	Married
BALWD#6	Male	51	D and OM	Christian	Married
BALWD#7	Female	49	D, OM and A	Muslim	Divorced
BALWD#8	Female	61	D, OM and A	Christian	Married
BALWD#9	Female	69	D,OM and A	Other religion	Married
BALWD#10	Female	55	A	Christian	Divorced
BALWD#11	Male	48	D, Om and A	Muslim	Married
BALWD#12	Male	44	Insulin, D, OM and A	Christian	Married
BALWD#13	Female	46	D, OM and A	Christian	Married
BALWD#14	Female	45	D, OM and A	Christian	Married
BALWD#15	Female	40	D and OM	Christian	Single
BALWD#16	Female	48	D, OM and A	Christian	Married
BALWD#17	Male	60	D and OM	Christian	Married
BALWD#18	Female	59	D, OM and A	Christian	Married
BALWD#19	Female	61	D, OM and A	Muslim	Widowed
BALWD#20	Female	58	D, OM and A	Christian	Married
BALWD#21	Male	58	OM and D	Christian	Married
BALWD#22	Female	51	D, OM and A	Christian	Divorced
BALWD#23	Female	47	A	Muslim	Single
BALWD#24	Male	53	D, OM and A	Christian	Married
BALWD#25	Female	53	Insulin, D and OM	Muslim	Married
BALWD#26	Female	62	A	Christian	Widowed
BALWD#27	Female	42	D	No religion	Single
BALWD#28	Male	47	D, OM and A	Christian	Married

Table 4.5. Special identification codes for healthcare providers (HCPs)

Participants (codes)	Role	Years of experience
HCP1DR	Doctor	20
HCP2DR	Doctor	22
HCP3DR	Doctor	18
HCP4DR	Doctor	24
HCP1NU	Nurse	18
HCP2NU	Nurse	22
HCP3NU	Nurse	22
HCP4NU	Nurse	19
HCP1DT	Dietician	14
HCP1NTE	Nutrition educationist	9

Table 4.6. Special identification codes for policy and decision makers

Participant (codes)	Role
PLM1	Policy manager
PLM2	Community and Engagement Manager
PLM3	Network and Policy Manager
PLM4	Policy manager
DCM1	Network and Policy Officer
DCM2	Health Commissioning Manager

4.8. Validity and reliability of data

The validity of data in qualitative study refers to the accuracy of data gathered that represent the participants' experience and the realities of the researched phenomenon. Therefore, qualitative research could be difficult and challenging to validate as the analysis carries an

element of subjectivity and personal bias. Therefore, Silverman (2004) suggested that reliability and validity could be achieved through the improvement of credibility of the research methods and data. From this perspective, it is important to ensure the consistency of the study procedures, their comparability to other research methods and the ability to verify and elaborate findings (Silverman 2004). Validation of the results occurs throughout the stages of the research process (as shown in figure 4.4). According to Creswell (2014, pp 201), *'validity is one of the strengths of qualitative research and is based on determining whether the findings are accurate from the standpoint of the researcher, the participants and the reader of an account'*. Creswell (2014) therefore recommended the use of multiple approaches to assess the accuracy of research findings. Some of the strategies identified by qualitative researchers to ensure validity and reliability in qualitative research are triangulated, researcher reflexivity, member checking, disconfirming evidence, prolonged time in the field, peer review, external audit, the use of rigour and clarifying bias the researcher brings to the study (Yin, 2003; Creswell, 2014)

4.8.1. Validity of the qualitative data

Data Triangulation

Combining and comparing the analysis of findings from different data sources is used to examine the evidence from the sources and build a coherent justification of the themes identified from the findings. Data sources were collected and analysed in a complementary manner to demonstrate trustworthiness in this study. The interviews were independently analysed, and the coding structure and findings were compared to avoid misinterpretation of information. Hammersley and Atkinson (2007) emphasised that triangulation is not simply used to control whether data are valid, but also to reassert that the inferences from these data are valid. Data from the different sources (people living with T2D, HCPs and policymakers)

were used in collaboration to create a complete understanding of sociological perspectives and opposing views of the research study and to test the strength of each finding (Silverman, 2011). For example, the results presented in this study draw on data from both lay observations and professional interviews to create an overview of the approach or ethos of each sample. Similarly, data from interviews with policymakers were interpreted and analysed within the context of information drawn from other narrative data from people living with T2D and HCPs interviews. Also, interviews with several people from different BsSA communities and health practices allowed cohesions and differences in experience to be identified, compared and explained (Creswell, 2014) (Figure 4.6). This broadened my understanding and enabled me to check my interpretations of the data from each participant and the credibility of each finding as described by Hammersley (1992). I also gave attention to suggesting explanations for exceptional cases, those whose accounts differed notably from other participants during the interview. This is not the question of not trusting what people allege but being able to put the data in context and triangulating it with other data sources to reduce bias. As Dingwall (1981) noted, the researcher, from this perspective, does not aim to “adjudicate between participants’ competing versions, but to understand the situated work they do” (Dingwall, 1981 as cited by Silverman, 1995, 158).

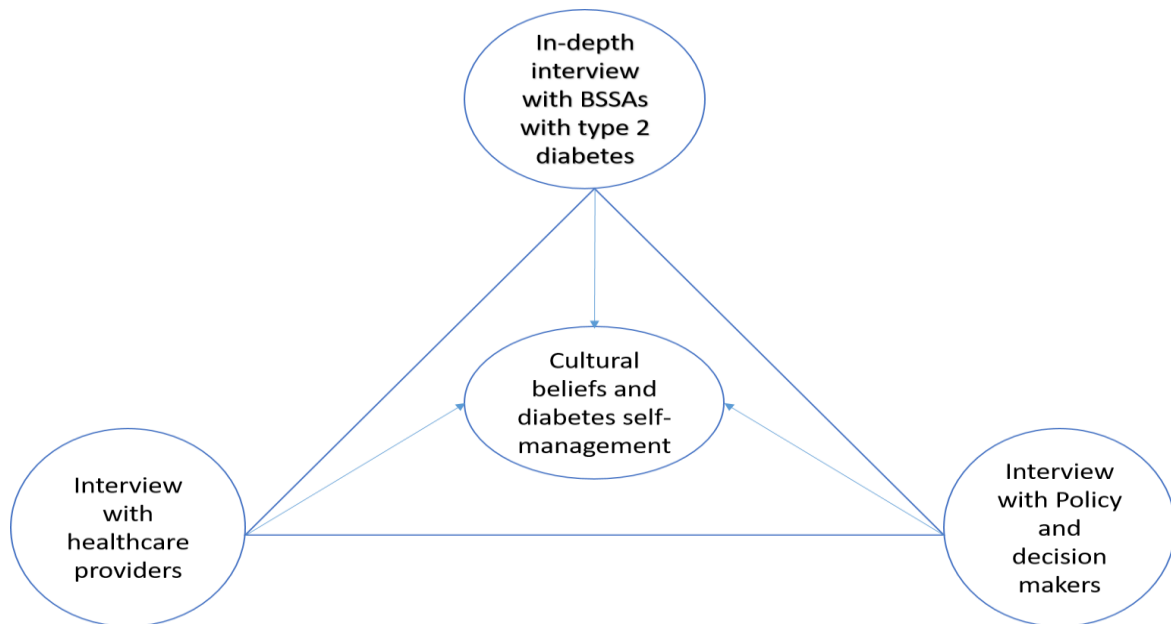


Figure 4.6. Triangulation of qualitative data from different sources (adapted from Patton 1999)

Researcher Reflexivity

Reflexivity describes the researcher's critical reflection on their role within the whole data collection process, and demonstrate an awareness of this, and how it may have influenced the findings to the reader. Seale and Silverman (1997) suggested that determining the exact nature of the closeness of a researcher to a study through reflexivity draws out the epistemological or theoretical stance of a subject. Otherwise, this can be achieved through establishing a researcher's distance from the data through the lens of objectivity (ibid). The assessment of data validity through the researcher's reflection as an ethnographer has been discussed in detail in section 4.3.3.3.

Internal and External Validation

Unlike quantitative researchers, who relies on the internal consistency of certain test scores in the context of measurement to reflect the robustness of the designs and tools, qualitative

researchers rely on the subjective lens established from the perspective of the researcher who conducted the research and the participants of the study (Creswell and Miller 2000). Through the lens of the researchers in a qualitative study, they determine data saturation and data analysis progression through repetitive review of the identified data codes and themes (Creswell and Miller 2000, Saunders et al., 2017). On the other hand, a qualitative researcher can assess data validity through the lens of the participants by comparing the accuracy of the data and ideas against the participants' perception of the authenticity of the investigated phenomenon (Creswell and Miller 2000). Internal validation includes techniques in which the researcher's account is compared with those of the research subjects to establish the level of correspondence and multiple perspectives among the subjects. Study participants' reactions to the analyses are then incorporated into the study findings. This represents a constructivist or interpretive approach and less systematic (ibid). In addition, assessing data through the lens of external individuals who are not associated with the research can also help in establishing the validity (ibid). At the end of the study, a discussion with the self-help group and other community groups explored the trustworthiness and completeness of these findings to clarify responses and to explore emerging themes of the research further.

To remove bias, the researcher avoided asking leading questions. Positive and negative worded questions were asked to ensure validity and reliability. Ethical standards were strictly maintained in the design of the questionnaires and interviews and ensuring that all respondents participated voluntarily.

4.8.2. Reliability of the qualitative data

In qualitative research, reliability relates to the dependability of the collected data. As such, assessment of trustworthiness is crucial to ensure reliability in a qualitative study (Creswell,

2007; Silverman, 2011). Precautions were taken to ensure that the research process was valid and written reflexively by giving a detailed account of the research process. The development of the interview question was based on the substantial theoretical basis described in Chapters 2 and 3. The interview schedule was first piloted to ensure reasonable, unbiased and valid data. Reliability in qualitative research considers the accuracy of conducting interviews, data processing and analysis. Thus, the credibility of the data was enriched by applying a good-quality recording device, verbatim transcribing of the recorded data and by maintaining consistency of information analysis and interpretation (Creswell 2007; Ritchie et al., 2014). Regular discussions on data process were held with supervisors and adjustments were made due to suggestions and recommendations. Developing a coded diary and using an external checking in the highly interpretive coding process is another means of obtaining reliability in qualitative data (Creswell 2007). The use of electronic software (Nvivo) to facilitates the coding process and data organisation also helped in the credibility of the data (see Appendix J).

4.9. Ethical Consideration

This study follows the guidelines for the ethical conduct of research set by the Nottingham Trent University (NTU) and British Criminological Society's code of ethics. Ethical approval was obtained from NTU's College Research Ethics Committee (see Appendix B). This step was necessary because the project involved collecting and analysing primary or unpublished data from, or about, living human beings. An official application form was required to be filled in and submitted alongside with other research, documentation, such as information sheets, consent form and interview schedules (see Appendices C, D, F, G and H). The ethical application was received and reviewed by the Ethics committee, and final approval was

received on the 30th of May 2015 to start data collection. This was following minor amendments to the original document submitted.

Participation in the study was voluntary, and participants' verbal and written consent was obtained before proceeding with the interviews. To ensure that our participants were appropriately and thoroughly informed, research information was verbally reiterated and presented in written format. Notes and audio recordings were used in the interviews with the permission from the participants. Confidentiality was assured by assigning a unique code number to each of the recruited participants and also referring to study participants by coded number rather than actual name during the research data analysis. Notes and audio recording were used during the face-to-face semi-structured interview with the permission of the participant. The collected data were stored in secured storage devices so that the confidentiality of the data would not breach. Participants were informed that primary data results would be destroyed accordingly after six months after the submission date of the research.

4.10. Limitations of research approach

The research used a qualitative approach to explore the role of cultural practices and beliefs on diabetes self-management behaviours in great depth. Nonetheless, the qualitative approach adopted limited the research sample and the number of cases that could be covered by the study. There was also a limitation about the generalisation of the result to a wider population of people with T2D among Black African communities in the UK. Since the samples selected do not actually represent a population, a valid inference cannot be made about a larger group from which the sample is drawn. Nevertheless, validity can be assured by random sampling with a more significant number of populations to avoid biased sample selection. Recruiting

participants from the NHS was also challenging due to the ethical issue, time constraints and medical representation of people living with T2D as patients. Participants were therefore only recruited from local organisations, self-help group, religious centres, community organisations and community centres. These channels, however, allow people to be seen more as persons rather than patients.

4.11. Summary

In summary, this chapter has described the processes that were followed in the planning and execution of the primary research data collection and analysis process. I discussed the epistemological and philosophical perspective of my study. The chapter discussed at length the methodological process, the sampling methods for the target population, data collection process and procedures for the semi-structured interview. It describes the analysis of the study and the use of Nvivo software for the qualitative data analysis. The limitations of the chosen methods as well as the ethical concerns and bias were also discussed in this chapter.

The next chapter (Chapter 5) presents the detailed analysis of the qualitative data, and subsequent chapters will be discussing the results obtained from the data analysis.

CHAPTER 5

EMERGING FINDINGS AND ANALYSIS

5.1. Introduction

This chapter explores the overall findings of the significance of culture and health beliefs on diabetes self-management behaviours based on the information generated from semi-structured interviews with BsSAs living with T2D, HCPs and policymakers, and their responses to culturally sensitive interventions to improve health outcomes. The findings are presented in themes and subthemes. Many of the themes were found in some cases to be crosscutting and overlapping due to the complex and multifaceted nature of diabetes self-management, beliefs and practices that the participant was attempting to share in their experience. An overall arching theme of diabetes self-management in an African cultural environment emerged during the data analysis process of this study. Special codes and numbers were used to identify each participant as presented in Table 4.6, 4.7 and 4.8.

This chapter presents the key findings from my analysis of data from a semi-structured interview with 28 Black Africans living with T2D, 10 HCPs and 6 policymakers. As described in the methodology, there are two phases of the data collection. Transcripts of the interviews were analysed through thematic analysis as described in chapter 4 (4.7.2.1). The themes and categories that emerged during the analysis of the semi-structured interviews conducted with the participants in the study are presented in figure 5.1 below.

<p>Research question 1 (Theme 5.2)</p>	<ul style="list-style-type: none"> • Cultural perception and knowledge about T2D among BsSA communities • <i>Cultural beliefs and knowledge about T2D</i> • <i>Perceptions about prevention and treatment of T2D – passive and active</i> • <i>Concepts of modifying African traditional diet and lifestyle</i> • <i>Perceptions about the increased incidence of T2D among BsSA communities</i>
<p>Research question 2 (Theme 5.3)</p>	<ul style="list-style-type: none"> • Self-management behaviours and lived experiences of the BsSA communities • <i>Level of adherence to medication, diet regimen and physical activities</i> • <i>Self-monitoring behaviour</i> • <i>Self-denial/self-blaming - self-disclosure about living with type 2 diabetes</i> • <i>Balancing health with social life</i> • <i>Challenges to seeking treatment services</i>
<p>Research question 3 (Theme 5.4)</p>	<ul style="list-style-type: none"> • The use of alternative therapies for diabetes self-management among the BsSA communities • <i>Cultural values of traditional medicine</i> • <i>Efficacy of Traditional/Alternative Remedies</i> • <i>Fear and mistrust of biomedical therapies</i> • <i>Religious beliefs and spirituality</i> • <i>Concepts of Healing</i> • <i>Contested perceptions about the use of alternative therapies</i>
<p>Research question 4 (Theme 5.5)</p>	<ul style="list-style-type: none"> • Health professionals' (HP) engagement with cultural values and health beliefs of BsSAs living with T2D • <i>Perceptions of HPs about adherence to treatment and support system</i> • <i>Difficulties challenging culturally embedded health behaviours</i> • <i>Professionalisation of support system – professional power on healthcare</i> • <i>Conflict of cultural perspective: lack of culturally sensitive information</i> • <i>The issue of disempowerment and ambiguity</i> • <i>Poor level of information provided by healthcare providers</i> • <i>Personal willingness and responsibilities</i>
<p>Research question 5 (Theme 5.6)</p>	<ul style="list-style-type: none"> • Perceptions on culturally sensitive intervention for self-management and implications for policy reformation • <i>Available networks for prevention and management of diabetes</i> • <i>Multiple challenges to culturally-sensitive diabetes intervention</i> • <i>Strengthening diabetes self-management as a means of improving health outcome: Collaborative practice</i> • <i>Use of alternative services for diabetes management</i> • <i>Diabetes care transformation initiatives through community networks: Integrative care</i>

Figure 5.1. Summary of the description of emerged findings related to research questions

Participants interviewed for the study

Forty-four participants were interviewed for this study. The demographics of the samples included in the study is presented in Appendix I while the breakdown of participants' sources and mode of interview is presented in Appendix J.

5.2. Perception and knowledge about T2D among BsSA communities.

During the interviews, participants described the aetiology of their diabetes, beliefs, opinions and perception about treatments and self-management, knowledge, attitude (stigma-related issues), misconceptions and health service utilisation. Participants also described the signs and symptoms, causes, risk and diabetes-related complications, prevention, treatment and the way of modifying African diet that could accommodate their diabetes. Some of the participants interviewed have previous knowledge about T2D before diagnosis while others were not quite knowledgeable. The majority of the participants were able to provide their primary source of information as families, friends, HCPs, internet and health programmes.

5.2.1 Cultural beliefs and knowledge about T2D

One of the major themes developed to explain the diabetes self-management behaviour was cultural beliefs and knowledge about T2D. Knowledge and perception in the context of this study refer to the lived experiences of BsSAs with T2D, and the shared facts and views by HCPs about T2D within the social and cultural setting of BsSA communities.

Participants' shared cultural beliefs about T2D' aetiology, causation, treatment, and symptoms coincide with the biomedical perspectives of diabetes. However, some of the participants overwhelmingly considered their T2D hereditary. They understood that this might have been preventable or delayed by eating healthier foods, not eating too many starchy and sugary foods, staying away from fast food outlets, losing weight, and regular exercise.

5.2.1.1. Perceived knowledge about the causes of T2D

Overall, awareness and understanding about diabetes were limited among some of the studied participants. Some of the participants were ignorant about the causes of diabetes before and after diagnosis. Prior to their diagnosis most of the participants acknowledged having heard about diabetes and the related complications. However, few of the participants had a comprehensive understanding of what T2D. Some of the participants shared their perspectives on the causes of diabetes and other ways that you can get it.

I have heard that if you urinate and you taste it... if it is sweet [sic], you have diabetes, and if it is not sweet, you do not have it. We call diabetes 'sugar' in my language. I understood this well when I was diagnosed with diabetes. My urine became sweet (BALWD#17)

I think type 2 diabetes can lead to type 1 diabetes if it is not well-managed (BALWD#21)

When asked whether medication could have affected the development of diabetes, a negative view was expressed by one of the participants

Oh, gosh yes, common on. Let us just say our medication come from a source like the bark of a tree or plant whatever and tablet is produced but we do not know what is put inside the tablets, we do not know the side effect of taking the aspirin, paracetamol or metformin. Again, we look at the doctors being gods and could remember the conversation I had with one of the doctors when he said I am going to

try you on this. Hold on, if you are a doctor why am I trying this, why am I not using this to reverse it, you understand what I am saying? (BALWD#24)

On the other hand, two of the participants understood prior to their diagnosis that diabetes could be transferred from one person to another.

I got the information even before I was finally diagnosed that my diabetes is infectious, so that I can pass it to my children and even my wife. (BALWD#11)

Yes, I believe you can infect anymore, especially those with intimate relationship. I was never diagnosed with diabetes until recently, and no member of my family has it, but I became diabetic when I got married to my husband... he already has diabetes. I am aware it can be transferred. How did I then get it if not through sex or let us say the fluid that passes through you both [laughing] (BALWD#15)

Participants described how the composition their traditional foods that are full of starch and fats could have contributed to their developing diabetes. However, they acknowledge their lack of proper management of their diet may have also contributed to the impact of the food on their health.

I was told diabetes are only caused by starchy foods, such as rice, pasta, bread and sugar... so I think I must have gotten my diabetes from the starchy food I eat ... my sugar level even gets too high each time I eat too much bread or fried plantain (BALWD#3)

Three of the participants, however, mentioned food as the main causes of diabetes

There was a nutrition book I read said that starchy food and sugar can cause diabetes and I had observed this before I was finally diagnosed with diabetes because I usually take plenty sugar. My friends once told me that I have sweet teeth (BALWD#5)

You only get it from sugar, don't you? When you eat a lot of sugar, and you have them stored in your body. (BALWD#14)

From what I know and read about, diabetes is caused by taking too sugary food, and you get high blood pressure when you add too much oil and salt in your food. I used to eat a lot of sugary stuff, and when it comes to traditional food, you need to cook the soup often with plenty oil. (BALWD#19)

Some of the participants identified the high consumption of industrialised processed food as the cause of the prevalence of diabetes. Canned and processed foods tend to contain many chemicals to prolong the lifespan as many of these foods are being imported from other countries, thus exposing individuals to the risk of diabetes and other diseases.

Many of us go for canned foods like canned fish, beans, sausage and tuna. because some of them were already half-cooked and easy to just put in the oven.... Within few minutes your food is ready. With so much information on media, we can now see that most of these foods are chemically processed, and they expose us more to diseases like diabetes... Of course, Yes. They do everything easy for us over here. Easy access to cheap food...unhealthy food. We buy everything from the store. We don't even

know how they produce them and what they use to preserve them. It's when I got to the UK that they write expiry dates on meat and different food we eat. Back in Africa, you get your food directly from the market... at most maybe they get harvested or produce in the last one or two day. You know, no need to preserve with chemical because we eat most things and cook them fresh (BALWD#1)

My mother has diabetes, but I did not have any sign of diabetes until I came to the UK and started eating fast foods from McDonald's and processed food, now with less time to burn this fat off my body, maybe because I might even be too tired to do exercise after a stressful day at work. I later realised that I get tired easily, my urine becomes sweet. You know, I know that if your urine is sugary, it is possible you might be having traces of diabetes and because I have heard from people saying they got to know about their diabetes because their urine was sweet. Well, maybe if I was still in Africa eating my traditional meal, I might not have it now (BALWD#7)

On the other hand, chemical preservatives in food were also reported as a major cause of diabetes

Increased chemicals in food. They preserved our foods with preservatives, and harmful chemicals are usually used as pesticides. All these make your food harmful to your body. This could lead to an increased sugar level in your blood. (BALWD#12)

Another participant believed her diabetes was caused by stress

When you are tired, you cannot cook. You will prefer to go to the shops to get fast food. When you have to do two jobs to earn a good income, where is the time to cook?

The stress of work gets you to have a high blood sugar level and to eat the wrong food only worsen it (BALWD#2)

On the other hand, few of the participants identified the distress of migration experience as the cause of their diabetes.

... personally, I had a distressing experience about immigration and living in the UK. The stress was too much for me, working longer hours to save up money so I can bring my family over to the UK. My health really went down the drain, and I begin to get sick and eventually diagnosed with diabetes. The stress was just too much to me both as a wife and as a mother to four children. You can imagine how difficult that could have been for me. (BALWD#20)

I do not know for sure what else could have caused diabetes for me other than stress. When you are stressed and you over-work yourself, it affects your body system. I only came to the UK about 15 years ago; it was not an easy journey trying to settle down in a different country (BALWD#23)

Lifestyles were also reported to be a contributing factor to developing T2D. Few of the participants associated the causes of diabetes with lifestyle factors, e.g. smoking, drinking.

... It all started with frequent urination, I was drinking a lot of water, and this became a big problem for me. I did not realise this quickly because I drink alcohol a lot and I smoke, and one of the main things that happen a lot to people that smoke, they tend not to eat well but drink a lot. So, at first going to the toilet often wasn't of a concern, but when it became too frequent even when I haven't drunk alcohol, then I

begin to think something was going wrong. I am sure diabetes would have been because of my excessive smoking and drinking. Even if your doctor tells you that you are at risk of developing type 2 diabetes, so you need to adjust your diet, if you still drink regularly and smoke, you will still have it. You could change your diet, but if you don't change other lifestyles that could also impact on your health, then if you are from a community like mine... well, they say we are more at risk of developing type 2 diabetes, then your diabetes will eventually show up over time. (BALWD#6)

I think my excessive drinking must have caused my diabetes. I have been through a lot in life and drinking seems to be a way out of my state of depression (BALWD#27)

Type 2 diabetes [sigh] this is about lifestyle... your pancreas is not producing enough or efficient insulin in order to disperse or break up the sugar content in your bloodstream. It is not necessarily what you are eating because your body produces glucose itself to keep you going. Many people do not know that. They think the reason why you have your sugar level up is that you have eaten something, but your body produces it yourself. The doctors actually say your pancreas is not producing; I am saying your pancreas is not producing enough, or it could be a blockage. Now, I think I have a blockage, and I will tell you why... If you check your lower belly button to the right, you have fats there; everybody has got it. Therefore, there are loads of fat, so maybe there is a lot of fat around your pancreas. Maybe your pancreas is working but has been blocked by the fat. (BALWD#24)

This participant went further to expatiate on the wider determinants of healthy lifestyle,

Yeah, genetic... but the bottom line is the lifestyle. Whether or not [sic], you will gonna get diabetes because your great-grandfather had it, my question is... because if you look back in history how our parents lived a healthy life. They did not drive that time; they walk plenty mile to go to work and walk plenty miles back, they work had in the field... The sugar in their system believe me is drained out and at the end of the day, they have worked really hard. Now our lifestyle has changed significantly with the likes of computers and technology, fast foods... We sit down a lot. Whereas our parent to work a lot and exercise through activities, but we exercise going to the gym. So, things have changed, and we need to recognise it. We have moved from our traditional food; we now eat pasta; many of our parents did not eat pasta. We eat sweet potatoes, now our intake of food is entirely different to what our grandparents and great-grandparents were eating. We have access to it, we put things in the freezer, that is not healthy, and we put them in the microwave instead of cooking properly, it is all different lifestyle changes that affect us and make us have diabetes. And also, going back to the manufacturing and production of food, they add loads of chemicals, modified substances... whatever they add to our food is eating up our bodies. For the children, I do not think it is hereditary; it is because of what they have put in the food that our children are now eating. Yeah, there could be part of genes that are being passed through our heritage, but it has a lot to do with our lifestyle. We need a fundamental change. We live in England, how often you see the sunlight we see in Africa. Our lifestyle and where we live is now affecting us. (BALWD#24)

Another participant acknowledged that diabetes is hereditary from observed signs and traits in relatives

Yes, I think it is hereditary to a certain extent. If a parent has, it is likely to be passed down to children. If the children lifestyle and activities are not monitored, they end up having it just like you (BALWD#12)

Although some of the participants acknowledged that diabetes could be hereditary, three of the participants emphatically mentioned they got it through their family gene.

My family on both sides have it; I was told my grandfather had it, so I was able to relate to it when I was diagnosed. I have always known that I would have it. Therefore, it was left to me to prepare myself and understand how I can manage it (BALWD#8)

I could sense that it might be diabetes when I started feeling weak, often, drinking regularly and because my brother experienced the same thing, the same signs and symptoms (BALWD#10)

I know my diabetes is hereditary because my mother and sister have it, but if I had been eating properly, not smoking, you know smoking usually prevents you from eating properly, and take care your body and exercise daily, I might have been able to prevent myself from it. (BALWD#11)

The participant went on to add,

...I do not think eating [sic] just starchy, and sugary food gives you diabetes. It is too many fatty foods and other lifestyles that make you diabetic. (BALWD#11)

Another participant affirms the causes of diabetes as being genetic but also related to lifestyle.

I do not know what the cause of it is, we have it in my family, my grandfather died of it, my mother had it, my aunties have it, and most of their children have it. We all have it in the family, some are on insulin, and some are not. It is a disease within my family. (BALWD#9)

5.2.1.2. Perceptions about signs and complications of diabetes

Although some of the study participants believed that diabetes was majorly caused by family history, diet, living a stressful life and lack of exercise, others have limited knowledge about the risk factors of diabetes and diabetes-related complications before diagnosis. Some participants believe that their illness became worse because of their transition to British lifestyle. The subsequent comments from four of the study participants demonstrate their prior knowledge before and after diagnosis and perception of their diabetes.

No... not at all, I did not spot any signs or symptoms until... a time when I fainted at work; I guess I was hypoglycemic at that moment. I was rushed to the hospital and later told by my doctor that I have diabetes... I have no previous knowledge about [sic] what could have caused diabetes before my diagnosis. (BALWD#1)

I think I must have gotten my diabetes from smoking too much and not eating, as I should. I knew I could get cancer from the cigarettes I take, but I never knew this

could also result in me having diabetes... the major sign of mine was my frequent urination, and I said to myself this is a death sentence. I know that once you are diagnosed, and you start your treatment, you will have to be on them for the rest of your life. Even when you try to change your diet, you still do not have full control over your body... other than to take medications sometimes (BALWD#6)

I actually got to know... by fault really, my previous role, I was a general manager in a very large company, and part of their activities was every two years we have a health check. It was at that point that it was identified that I have high blood sugar level, but I was not aware of it at the time. Then, I was referred to my GP, and later they diagnosed that I had type 2 diabetes. (BALWD#24)

According to some of the HCPs, most people are usually not aware that they have diabetes because some of the general signs and symptoms of diabetes can also be seen in other diseases such as cancer, kidney problem and flu, and daily experiences of life such as a stressful day at work. Some might assume it to be a change of weather or diet.

Many of the patients that we have seen in our clinic were not aware that they have diabetes until after they were diagnosed with it. Some of them simply came with symptoms assumed to be related to other illnesses or ones that they could not figure out what it could be. Some of them will tell you they have used some home remedies or self-medicate but still not get better (PRC3NU)

Some of them might think it is the change of diet that has resulted in them losing weight (PRC1DT)

Similarly, few of the participants reported that they were not sure of the causes of their diabetes because of similar signs of other illnesses. Therefore they could not identify the signs quickly.

I do not know... you know it just happens. I thought I was doing everything right with my health, but of course, things went wrong... very frustrating (BALWD#16)

I am aware few things can cause diabetes, but I really cannot say what exactly causes my diabetes because I did not have any major signs.... You know, as the doctors will say that one will be experiencing this or that... I did not have any of those major signs (BALWD#26)

Although some of the participants were unaware of the different type of diabetes and related complications, some could recall the medical knowledge about diabetes.

Type 2 diabetes happens, when your pancreas does not work very well or not strong, enough to secrete enough insulin that can help you regulate your sugar level. If the sugar level is too high in your blood, then you become really tired and sick. (BALWD#5)

This is where it becomes funny because after 25 years I should know what it is [laughing]. Type 1 can be controlled by a tablet, and type 2 is insulin dependent, but I might have switched it around. I think its cause when the body does not have enough insulin to regulate sugar intake or the breakdown of sugar. The body requires

additional support to control the sugar, which is when a tablet or insulin then needs to be taken to help. It is either limited or lack of insulin, which is hormone deficiency. You are prone to infection quickly because the body immune becomes weak and overworking itself and not able to withstand additional pressure. There is also potential blindness from glaucoma and affects the extremities like hands, feet, and body doesn't heal as fast as a normal person (BALWD#12)

Two other participants mentioned that the risk of diabetes could be enormous and the complication life-threatening.

I remember there was something I was told and read about, and this was very upsetting and frightening... that I can lose your sight and limbs as you grow older if you have diabetes.... since I was diagnosed with type 2 diabetes this information always ponders in my mind every day that I will lose my sight and limb someday... I feel I have little or no control over my diabetes and see it as a death sentence (BALWD#4)

... you might think this disease is just for old people, but I tell you it can affect anybody. The rate at which our children eat processed food and drinks now is really disturbing. The numbers of obese children are growing day by day. They do not even want to eat proper food anymore. Yes, there is some medication prescribed that could manage diabetes, but the complications are frightening... you can lose your limbs and sight (BALWD#18)

Other participants also emphasise the importance of being tested before concluding on diagnosis:

Well, I use to test my urine myself, and I was diagnosed in 1991, so about 25 years. My doctor was retired, so I had to join another practice... what they do, they do an overall examination of everything, and they find it in my urine. So, they did the test... glucose tolerance test. Well, I use to be very tired and drink a lot, but of course, you pass it on... I have the notion that possibly, I would be but I did not know until I had the test. I felt dreadful... Dreadful, when the doctor told me after they had my blood test and she gave me the result, instead of walking straight home, I walked all the way... you know the consequences of what it can cause, and then you should be so careful, but you know after having knowledge about it you just live normally. It's better you know than never. (BALWD#9)

According to some of the participants, HCPs, media, friends and families added to their knowledge about T2D signs and symptoms before being diagnosed.

I realised I wanted to drink more, and I feel tired easily, so I just googled it to check the symptoms I was having at that point so I discovered it might be high glucose level. You know how you cannot really rely on the internet when it comes to your health, so I called my GP to book an appointment for a blood test. I met with my doctor, and she told me that I have type 2 diabetes. I almost fainted. (BALWD#13)

My doctor friend works with diabetes patients. Many times, I have heard him talk about diabetes and the risks. There was a time we watched a movie together, and

there was a man the doctors had to cut off his foot because of infection, and I remember him telling me the reason why they had to amputate the foot was that the man had diabetes. His wound will not heal up quickly, causing further infection if they do not cut off the foot. That made me worried about having diabetes. But then I was later diagnosed. I told my doctor friend, and he said I should not worry too much about it, that I will be fine if I am able to manage it properly (BALWD#18)

I did not get to know that I might be diabetic until one of my friends called my attention to me complaining of [sic] going to the toilet often and regularly being thirsty. She advised me to go for a test, and that is how I knew about it that I am diabetic. (BALWD#22)

A very good friend of mine is a GP, and I call him quite a lot, and I asked him loads of questions and because He [is], not my GP, so he is more open. He tells me this is not what they actually meant; this is what they are actually trying to say X, y and z. (BALWD#24)

On the other hand, two male participants could confidently share his experience of how he got to know about his diabetes through his sexual experience.

My back always hurt whenever I am with my wife; you should understand what I am saying [laughing]. At first, I thought it was because I was eating too many sugary stuff, but I have to know later that it was my blood sugar level was constantly high. (BALWD#11)

You might find this funny, but it is a true story. I realised that I was losing the ability to be sexually active with my wife and I became very concerned. You understand how this can affect marriages, especially when it comes to the suspicion of you have extramarital affairs. I had to call my GP for an appointment before my wife started asking me questions. So, I...explained to him the way I was feeling how long I have been feeling that way. I eventually was diagnosed with diabetes after a series of blood test. (BALWD#28)

Many participants, however, acknowledged that people from the African origin are more at risk of diabetes and complication because of their comfortable western lifestyles.

... I do think Black people in the UK.... you know what I mean...they are more of the risk of diabetes and complications because we are increasingly eating a lot of refined fatty and sugary foods in our diet and doing less exercise. We focus more on our income, working and working all day long without looking after our health (BALWD#17)

5.2.1.3. Experience of T2D diagnosis

Participants described the symptoms of T2D as regular urination, frequent thirst and, dizziness, excessive sweating and hunger, loss of weight, fatigue or the lack of energy, numbness of feet and toes, wounds taking a longer time to heal, and poor eyesight. However, some of the participants described how this could be misdiagnosed.

I did not take it seriously at first. I realised I was feeling dehydrated quickly, even after taking water. However, it was during summer, so I thought it was just a reaction

to the weather. I mistook my symptoms for something else. It was after, many months when I realised I was not feeling any better that I decided to have an appointment with my GP and later diagnosed with diabetes. I could not believe what I was hearing from the doctor; it sounded like a life sentence to me. He later told me if I had not come on time, it would have affected my kidney. (BALWD#2)

I realised that my eyesight was getting worse and I did not understand what was happening because we all have bad eyesight in my family so I would not have thought there was anything else happening to me. However, I got concerned when I began to feel really thirsty and going to urinate often. It was very traumatic for me when I was finally diagnosed with being diabetic (BALWD#16)

Another participant described her symptoms before diagnosis:

I noticed I was losing weight, I do feel hungry, but I just do not want to eat but drink juice or coke. I lost a lot of weight, and I was becoming sick. When they tell you if you add too much weight, you have the risk of having type 2 diabetes, mine was different, and I was losing weight. I was concerned, so I went for blood test and was finally told that I have diabetes, I became confused about why I should have it when I was not adding weight. (BALWD#19)

Participants believed that when small ants surround your urine, it is meant to be the sign that you have T2D because of the sugary taste of the urine

I got the feeling of whether I have diabetes when I travelled home to Africa for a holiday and realised that in less than a minute, small ants were already coming near my urine, I was worried that I might be having a high sugar level in my blood. (BALWD#15)

There was no way you can just urinate anywhere you like here in the UK. No way ants can just surround your urine, so a friend of mine after I have complained to her about the way I was feeling, she told me to have a taste of my urine, and if they are sugary then I need to see my GP (BALWD#17)

... your urine is usually sweet when you have diabetes or if you can smell that sweetness. You know, sometimes you can smell when something is sweet, and that tempts you to want to taste it (BALWD#21)

Nevertheless, two participants believed that physical inactivity was not directly related to their diabetes. There was no extra time for other physical activities, as stated by the participants.

House chores like cooking and cleaning the house are enough exercise for me, so I do not think my diabetes was because I was not exercising (BALWD#8)

I don't take breakfast, so I tried to eat heavy dinner so that can keep me until lunchtime. Therefore, it must have been because of the portions I take before bed not just, because I do not exercise. If you eat heaving food late to bed, it doesn't digest easily, and that causes harm to your body (BALWD#25)

On the other hand, one participant shared her experience of how her diabetes has improved because of exercise.

I think exercise works better for me than going strictly on a diet. I try to exercise more these days because I feel if it is not because of my exercise, it may have gotten worse. I try to eat lots of vegetables and fruits. Just ensuring that I balance it (BALWD#9)

One of the participants reported that his diagnosis was a shock to him because he thought he was living a healthy lifestyle.

No... not at all. I became really shocked when I was diagnosed with a severe eye condition due to diabetes, but I was not aware of that either. It came a bit of a shock when the doctor told me you have diabetes, and I am like are you sure? You know I have lived a healthy life; you know I do a lot of... my eyes checked; the way I got to know I had diabetes was quite a bit of a shock to me at the time. If you have it, you do not know until they tell you. Oh yes, I realise I use to feel a bit faint then or maybe you think you've had too much... oh yes, I do feel a bit tired... you might feel oh well, I'm feeling run down or tired you don't actually think it's this condition that is causing it. There are a lot of people with diabetes that don't know they've got it..... You may be displaying only one of the conditions, you know, maybe you're drinking a lot, or you're going to the toilet a lot. However, you know you have not actually linked that to any health condition, or think that you have diabetes. (BALWD#24)

5.2.2. Perceptions about prevention and treatment of T2D – passive and active

Perception about prevention and treatment of T2D was another theme identified to analyse the understanding and view of T2D. When participants were asked about the prevention of T2D, some of the participants believed that diabetes was not preventable and some hope for a cure. This perception was mostly because of the religious beliefs that diseases befell human beings when God punished man.

...this has always been so right from the beginning when God created man and man sinned against God. One cannot really prevent yourself totally from getting diseases, only by God's mercy. (BALWD#4)

We have this illness because when Adam sinned, God cursed him, so it affected the whole creation, it's only God that can make things right. That is my belief. No matter what the doctors say, these things will happen, will continue, and will get worse, especially now that we are living in a critical time as the bible says. The doctor and medical people will try their best, but they cannot fix it. The sin that man committed, and we inherited, and because there is a curse on it, we inherit it. (BALWD#9)

It is up to Allah. It does not mean that it will be diabetes that will kill you, anything can happen at any time, whether sickness or something else. (BALWD#13)

Some participants emphasised the fact that because T2D is passed on genetically, it has become impossible to prevent it.

How can you prevent yourself from getting it when you know it will be passed to you genetically? (BALWD#8)

My mum indirectly diagnosed me. My mum is diabetic, so she noticed my symptoms were like hers, so she took me to the hospital and then I was diagnosed. I knew I could not have been able to prevent this if my mum already had it (BALWD#12)

Another participant supports the argument that diabetes is not preventable due to the lifestyle of the society. She said,

There is no food we eat now that does not have sugar. The society and government are killing us all. Nobody goes to farm anymore. We rely on the food we get from Tesco, Asda, Saturday market and the rest of them. Do you know what they use to grow and how they modify their food? So then how do they want you to prevent diabetes? (BALWD#7)

While some of the participants discussed that prevention was impossible due to the underlying genetic causes and spiritual beliefs, others believed that T2D is preventable. They mentioned that since diabetes is often caused by unhealthy diets and lack of exercise, it could be prevented with individual taking responsibilities of ensuring they live a healthy lifestyle, eat a proper diet and exercise regularly.

...yes, it might not be curable or treatable, but you can prevent yourself from having diabetes by ensuring that your lifestyle is not a risk to your health, eat good and healthy food. Not just good but healthy food and doing exercise, not just walking 2

minutes from your house to the bus stop. Personally, I love to walk more now compared to before, and it was because of my weight. I was overweight, so I don't like to walk. I come back from work and just relax because I know I will be having another busy day at work the following day. However, things are different now. I walk a lot now. So maybe I would have been able to prevent this diabetes if I was exercising more. (BALWD#6)

If I were not a smoker, I probably would not have had it. (BALWD#11)

Concerning the treatment of T2D, perceptions and understanding of the concepts of treatment among participants appeared to differ from each other depending on their experiences. Those who associated the measures of diabetes treatment with total cure appeared to be convinced that diabetes is not treatable or curable. This belief was perceived as important based on their long-term experience of receiving medications without being cured of diabetes. Others based their views on the experiences of families and friends who have been suffering from diabetes and had related complication for years without any cure. Some of the participants expressed their views as stated below

... since I have been diagnosed with diabetes for 18 years, even though I use my medication as recommended, I have not seen any sign of a major change that will convince me that this condition is treatable. I would rather say it is more manageable than treatable. My eyesight had really gone worse compared to when I was first diagnosed. I know it is mainly because of all the medications I take but I am yet to be cured. (BALWD#3)

Since I have been attending the diabetes clinic, I still see the same set of people that have been coming for over the years. Maybe new ones, but that should tell you they do not have a cure for it. (BALWD#11)

If you look after yourself... but no matter how you look after yourself, it will become a bit worse later in life. (BALWD#17)

... the treatment extends your lifespan for some extra years if you keep a good check of your lifestyle and monitor your glucose level, but it is not curable. (BALWD#21)

Similarly, an insulin-dependent participant appeared to be less convinced about the possibilities of preventing or curing any types of diabetes.

Diabetes is not curable. I have been diagnosed with diabetes for over 30 years, and insulin dependent and my health is still the same. The treatments doctors give you, either insulin injection or tablets only control the sugar level in your blood, it does not cure it. They advise you to avoid certain foods, reduce sugar and salt intake but all the major food we eat have sugar and salt directly or indirectly. (BALWD#5)

One of the participants with T2D, who is also a nurse, expressed her concern about the lack of evidence from anyone to support the claim that people can be cured of diabetes

I have worked in the health sector for 20 years, and I am a nurse. I have never heard of anyone who came back to tell us that the medication we gave him, or she has cured his or her diabetes. (BALWD#25)

Two other participants affirmed this view:

The fact is that this disease is not curable. Once you have it, you have it for life. It is part of you. I have had this now for a long time, and I am yet to see anyone tell me that their doctor gave them medication and they were cured of diabetes. (BALWD#4)

It is treatable, but I would say not curable. People seem to throw information left, right and centre about it been curable but proven. No. it can be managed, but it cannot be cured. Not because I think it is not curable, but because so far, no drug has been put out there to say diabetes can be cured. The drugs out there is more for management. It is very possible with the use of alternative or traditional medicine, but personally, I have not seen any yet or met somebody who was officially diagnosed with diabetes and has been cured (BALWD#12)

Similarly, another participant expressed the uncertainty of whether diabetes can be cured or not, but interested in the cure if eventually discovered.

Some people say it is curable, but some people say it is not... I have no idea if it is curable. It will be nice if it can be totally treated and cured and very well if I don't have to worry about what I eat, or I should live my life based on what doctors say (BALWD#9)

Few other participants who know the medical treatment and dietary requirements for diabetes emphasised that the treatment that they were getting from their GP was mainly meant to help

control their glucose level and treat other sickness but not to cure their diabetes. Two of the participants stated:

... one may feel much better, your glucose level might go back to normal after taking your medication, but it doesn't cure you of diabetes completely (BALWD#1)

The medications only keep your diabetes under control. There is no cure at the moment [sic]. (BALWD#6)

Correspondingly, two of the diabetes nurses interviewed supported the arguments. She stated,

The medications we prescribe to the patient is meant to help them control their glucose level, and some of them might have other health conditions. So, if they take more medications to help for general wellbeing (PRC2NU)

The medication, prescribed with other treatment regimens is to assist patient control their blood sugar level and reduce the risk of complication (PRC3NU)

However, few other participants believe that diabetes is treatable, and one can eventually be cured of it if they take all the necessary precaution, good diet, exercise regularly and have self-control or belief in any treatment they take for their diabetes.

Proper adherence to treatment, diet restrictions and doing some exercises could eventually be cured of it. There was a time that my diabetes was really bad, but since

I have taken out some diets, I take more of herbal tea rather than juice or normal tea, I do more of walking than taking the bus or driving a car, I feel a lot better now and relaxed. Moreover, I believe if I continue this way, I will eventually be cured and my sugar level will be normal. (BALWD#2)

It is a thing of the mind. If you do all that is expected of you to do. I believe you will eventually overcome the condition. (BALWD#7)

Yes, yes... I understand there was a report in the 1930s and they actually found a cure for diabetes, and a very large pharmaceutical company buys that, and no one can touch it, no one can see it. Is it that not interesting? Think about it; a pharmaceutical company, do they want to give you the cure? No, because if they give you a cure, they will no longer be in the market. You know; therefore, they keep giving you tablet instead of giving you a cure for it. Of course, there is a cure for cancer, but do the NHS, doctors or pharmaceutical companies want to give you a cure, no, it is for their own interest. They will keep you on medication... keep giving you the tablet. It is more of their interest to keep you alive and not to cure you. I believe there is a cure. (BALWD#24)

However, when the participant was further asked if he thinks the diabetes was preventable, He said,

Yes and no. In the environment that we live, we have relied on others to produce our food, and that is the key thing to our diabetes, is the food we eat. If the government does not rely on, get really heavy handed to the manufacturers that add too much sugar and salts to our food, then diabetes will keep occurring. African communities

are starting to suffer more from diabetes, and it is because we are moving away from our diet. We see more of our people going to MacDonalD's, staying away from our natural and traditional foods. (BALWD#24)

Similarly, another participant affirms the view that diabetes can be prevented with lifestyle changes.

Yes. With the African food that we eat, it might be a little difficult, but you can still prevent it if you eat healthy food, do healthy exercise... you know there are some exercises that are not actually healthy. They could cause damage to your body. As I mention earlier diabetes has a lot to do with our lifestyle including diet and exercise. (BALWD#1)

While some participants were convinced that their diabetes could be treated and cured by adhering to medical treatment, diet restrictions and regular exercise, some other participants were convinced that diabetes is treatable and curable, highlighting the spiritual role and the use of traditional and natural remedies in the treatment and cure of diabetes.

I have placed myself completely on natural remedies for months now, I feel much better and I know I will be totally cured of diabetes (BALWD#10)

I am sure God can and will heal me completely because I am his daughter and he always looks after me. (BALWD#23)

The discussion on the use of traditional and alternative remedies is later elaborated upon in section 5.4.

5.2.3. Concepts of modifying African traditional diet and lifestyle

The modification of traditional African diet was another theme that emerged from the study data analysis of the knowledge of diabetes. Participants struggled to merge the biomedical recommendations for effective management of type 2 with their preferred African diet. In response to the Cultural Beliefs about T2D self-management and other lifestyles that influence self-management behaviours, many the participants were interested in keeping their cultural values.

In the interviews with the 28 Black Africans with T2D, many the participants described how they considered traditional African diets to be high in starches, sugars, and fat content but rich in fibre and Iron. Many of the participants reported the benefits of eating naturally grown food. However, they acknowledged that large portion sizes per meal and cooking patterns could further worsen and undermined their ability to control and maintain healthy glucose levels. One of the participants stated,

... though you often feel you will get more energy eating our diet (shoulder sign), but then it is all filled with lots of starch... and if you do not balance your diet with another nutrient, it becomes harmful to your body. (BALWD#3)

Another participant agreed with this view.

You need to change your lifestyle of relying on traditional diets and the way you cook it because of what they contain. You want to avoid doing yourself any more harm than good (BALWD#13)

Although many of the participants said that they recognised that they needed to cut down the quantity of starch, carbohydrate and fat in their diets based on a doctor's recommendation and diet guidelines to efficiently treat T2D, they were more centred and concerned about how to successfully modify their African traditional diet rather than ruling out their foods completely. The main measures were balancing healthy African traditional food with green leafy vegetables, brown rice, chicken, fish and less sugary fruits.

You just need to eat things in moderation. If you eat too much of fast food, you will get obese and have more chances of developing type 2 diabetes. So, just try your best to eat foods that are healthy. I still value my traditional food that all this their western diet anyways (BALWD#7)

My greatest challenges are festive periods like Christmas and Easter, you eat with families and friends, but I always remind myself to eat in moderation. (BALWD#10)

I have not changed my diet since I have been diagnosed, I eat what every other person eats but I eat in moderation. This has not made my diabetes worse in any way. The truth is, the more you worry yourself unnecessarily about what to and what not to eat, you are killing yourself mentally, and that will then affect your health. So, what do you do? Just eat in moderation, control your consumption of sweet things, and be happy. (BALWD#15)

One of the participants emphasised that what you keep around you affects your decision on what to eat.

How will I be able to manage or control my diet when my cupboard and fridge are all filled up with sweets, savouries and all sorts that will not help me? You need to keep away from them sometimes to help yourself. I make sure that whenever I go to African shops, I buy fresh vegetables and other fresh food. I do not usually to go all these supermarkets and savoury stores, the more you go there, the more you are tempted to want to buy things not good for your health (BALWD#9)

Despite the efforts of participants to modify their traditional diets, some were unsure and concerned about appropriate consumption and portion sizes and admitted that they often ate large amounts of traditional African foods, starches like white rice, pounded yam, wheat and other heavy food. Participants discussed how difficult it was to substitute brown rice for white rice or white bread for brown bread, which are staples of the traditional African diet. Participants who lived with families and big household stated that though their family was supportive of changes to their diet, they still struggle to adjust to it.

It is very difficult staying on a diet when I have to cook for the others; you can only cook one pot and not two. Most of the times I have to take out my own portion before [sic] seasoning the rest. You understand the pain of doing this every day. But most of the time I don't do it, sometimes in a hurry, I'll just cook for everybody or I just cook enough portion for just myself which I know can last me for two to three days. (BALWD#2)

My wife likes to cook our traditional meal, and that makes it sometimes upsetting when I don't eat because she does not understand. Putting in all the effort to get me one of my favourite food and then I tell her I cannot eat it, you understand this can be very upsetting for women. She wants to see me eat, but she ends up getting upset when she cooks, and I tell her that I cannot eat it. Women take this as being inconsiderate, you know. She obviously wants me to be healthy, and she meant no harm [sic] cooking the meal, but I try most times to explain why it is not good for me. I think she is beginning to understand when I say I want a specific meal, but it is really hard to live with a strict diet plan when you have a family that you mostly eat together. (BALWD#17)

In contrast, many of the participants believe that eating a traditional African meal is good for managing T2D because of its composition and natural nutrients contained in them. They believed that there are more chances of them not developing T2D if they still live in Africa. They also believed that they would be able to manage T2D if they still lived in their country of origin because of easy access to alternative medicine or herbal remedies. They talk about eating fresh food, fruits and vegetables and often walking to farm as a form of exercise. They also mentioned enjoying doing, these activities each time they go back to their country of origin might be to visit or holiday.

Our food is not the same as what the western people eat, especially here in the UK. It is inorganic and processed. In Namibia, most of the food that we ate comes directly from the farm, no chemicals to preserve it. No inorganic food and most of our food is not as starchy and fatty as what we get here in the UK. We eat fruits and vegetables

directly harvested from the farm. Well [sigh] our weather will not allow you to preserve things for longer days, so we eat them quickly. (BALWD#1)

The way you live at home in Zambia is totally different from the way we live here in the UK. We don't work long hours when you eat; you have time to walk around and exercise; there is less stress as compared to how I live here. Basically, you have more time for yourself and your family. We entertain ourselves more socially, visit friends and families, but here in the UK, there is virtually no time in visiting people when you work at different times. I honestly do not think that I would have had diabetes if I was still in Zambia. The food we eat is different and fresh. We also have places like McDonald's and other restaurants where you can eat out on the road, maybe when you are travelling, but we do not make it our main meal. However, when I got here, I gained a lot of weight, longer hours of work; there is really no time to do exercise because you are already tired from a long day at work. The food here is so very cheap and chemically preserved. You do not have a farm of your own because there is no space. I have a garden, but how many things can you grow there? Fast food has become part of you and everyday things... and I have noticed here that kids prefer to eat out, so you most times end up eating out because of them. (BALWD#8)

Participants emphasised the belief that their diet would be better in their country of origin compared to western countries, and that they engaged more in physical activity. One of the participants stated:

When I'm back home in Zimbabwe, I get to do more exercise because I try to visit friends and families and you do this often by walking. You often do not get to do this here in the UK (BALWD#6)

Back home in Cameroon, I was more active. We did a lot more exercise walking and going for hunting or helping families out on their farm. Our foods were fresh, more natural and greener... not processed. Back home a lot of our foods came directly from the earth; we have our own fruit trees in our compound. A lot of the stuff that we ate and drink back home are mostly medicinal for you, and you have the time and energy to shed off any fat because of our hot weather. (BALWD#11)

Compared to how they live in the UK, some participants firmly believed that their diabetes got better when they travelled back home to Africa.

... would you believe that whenever I go home for a holiday, my diabetes disappears? I never take my medication. (BALWD#15)

When this participant [BALWD#15] was further asked why she did not bother to take her medication, she replied,

... because there is no need for it. I eat good and fresh food. There is good hot weather to burn off excess fat. I feel good about my health, my sugar level goes normal, but when I arrive back to the UK, it is a different story [sic] it is gone higher again. You do not get to do much exercise here. There is a bus stop at every other 3 minutes away. Where, you know, you can get good food, is either not affordable or

not easily accessible. Travelling to farms in the countryside so you can actually get something good... that is too expensive. (BALWD#15)

Most of the participants emphasised the importance of self-managing their T2D by modifying their consumption of traditional African foods over increasing physical activity. It should be noted that many of the participants realised the importance of physical activity for T2D self-management.

If you are going to keep to eating your traditional food here in the UK, then you need to do more physical exercise than you just going up the staircase in your house, thinking you can lose weight by just doing that. Living somewhere in Africa with a hot climate condition might be better for your body, but over here in the UK, you need to learn to do more exercise of the type of climate condition here. (BALWD#4)

In contrast to whether living in Africa would have reduced the chances of developing diabetes, three participants stated,

I have immediate families that live both in Africa and in the UK, that has diabetes, but I think living in the UK may have contributed to mine or maybe I found out faster than I have it because I live here. We have a good health system compared to some places in Africa. People often are misdiagnosed as something else in African or just self-denial that they do not have it or they do not believe in it. (BALWD#5)

I do not think so. Personally, I have a younger brother who lives in Africa and has never lived in the UK but has it. Well, in England, one must work very hard, getting

up dreadful and working night. You try to keep awake all night... I think these things affect my health generally. I think so... that it's possible all this will have led to it. It is really awful; I mean the lifestyle in the UK (BALWD#9)

In support of this argument, one of the participants stated,

No, because where I come from in Africa, health care is not as detailed as it is here. The kind of information you get over there is very limited compared to what you get here. Then, when it comes to things like feeding there is a wide range of option here especially for Africans. It is a cultural thing that you eat starchy food, and starchy foods are sugar. We are trying to control it, not completely taking it out, but controlling it so the body can balance your nutrient. There are alternatives to starchy food in the UK (BALWD#12)

Participants' cultural beliefs about how to effectively self-manage their T2D influenced the decisions that they make about their traditional food choices and the mode of preparation daily. This cultural belief about modifying of traditional African diet is a fundamental component of the Black African belief about T2D self-management.

When I want to prepare my traditional food, I try to use less fat and reduce my portion size to manage my diabetes. (BALWD#13)

I reduce the fat around my weight, again the doctor says you need to lose weight, no, you need to lose fat around your tummy.... there is a difference there. That is the areas you need to work on. However, people think they do loads of exercise but there

is still fat around the tummy, and this could be affecting your pancreas from producing enough insulin. I measure my tummy now, and I am trying to bring that down.... I am 24 now. What I also do now is that I have reduced the quantity or the portion I take and then I only use a quarter or half of the quantity of oil I would have used to prepare my food. Diabetes should not stop me from eating my traditional meal if I want to. (BALWD#24)

On the other hand, though many of the participants showed concern about the composition of the African diet, one of the participants acknowledged the importance of keeping cultural values

Our diet, what we eat and the whole process of cooking, what we add in it has a lot to do with the way we get susceptible to diabetes. Some cultural values will remain with me. If we give up our culture, I think we will lose more. I think what we should do is to do more research and see how we can make our culture work better instead of throwing the culture completely out. We can develop drugs that can help people like us from the African descent digest our food better without harming us (BALWD#12)

This section examines the knowledge, perceptions and cultural beliefs of people with diabetes and HCPs. The findings showed that knowledge and awareness among participants about diabetes were insufficient to help improve health behaviours. Most participants were unsure about the causes of T2D although the majority associated it with a high intake of sugar and starchy food. A few participants mentioned the causes of diabetes as genetic and failure of the pancreas to produce enough insulin in the body to help control sugar level. However, others associated the causes of diabetes to spiritual and religious beliefs. The main sources of

knowledge about T2D for most participants were family members, neighbours, the media and HCPs.

The findings also revealed a high level of uncertainty among the participants concerning whether diabetes can be prevented, treated or cured. Although many the participants with T2D were unsure about the possibilities of being cured of diabetes, they were convinced that the treatment does prevent further health complications. Most patients, for example, acknowledged that they were more vulnerable to diabetes complications if they did not adhere to their treatment regimen. Many of the participants reported that modifying diet could improve or reduce the risk of diabetes. The next major theme identified explores the differences in management behaviours.

5.2.4. Perceptions about the increased incidence of T2D among BsSA communities

Most participants interviewed in the study acknowledged the increase of T2D among the Black African community. According to the participants, the growing rate of T2D in the Black African communities was attributed to several factors including the changing lifestyles of the population, nutrition transitional and lack of public information about diabetes among the population. Participants stated that lack of information affects both healthcare-seeking behaviour and overall adherence to the treatment regimen. Specifically, the HCPs interviewed during this study agreed that changes and transition in nutrition and lifestyles, particularly among the African communities, have been contributing to the increase in T2D.

Diabetes is a big problem in our community, especially among the Black African community because of lack of awareness and ignorance of people. Going for treatment or diagnosis at the hospital is not always the first call for people. People

self-diagnose, self-medicate, and some just ignore it because of beliefs or other commitment. (BALWD#1)

Many of us are at risk of type 2 diabetes because of what we eat and our lifestyle. We want to live the western culture, forgetting that the way our body system works is different. It is a big problem (BALWD#6)

My biggest problem is misinformation among the community, lack of information, cultural impact and influences. There is misinformation about the diagnosis. Lack of information in the sense that people hardly know or able to spot signs, and this leads to some of the complications that can be avoided or reduced to happen. Many times, we have incidences where limbs are lost, and the patient has gone blind because they have been misled or given wrong information. If a patient does not know, at least a medical person should be able to say that you know what, you should check out yourself in the clinic. However, most of us, we, Blacks, we keep to ourselves and do not share information quickly (BALWD#12).

One of the participants affirms lifestyles and diet as a major reason for the increased incidences of diabetes among the BsSA communities.

... I would say the main reason for the increasing prevalence of diabetes among Black African communities are the growing change in lifestyles and diet. We are increasingly eating a lot of fat and oily foods contained in our traditional diet as well as higher sugar levels in other English diets that we eat to supplement some of our traditional diets. People are increasingly relying on processed and refined foods and

less active. We use more of public transport even for short distances, which could easily be covered on foot. I understand to some extent why the government tries to make our transportation easy, having bus stop every other 2-3min away, but this is rather causing people to be less active (BALWD#17)

Another participant affirms the lack of health information and effective communication from the HCPs.

There is still limited information as not as much as you would expect to hear about diabetes. You hear information about cancer almost every time on the Television and social media, almost 24hours you hear about cancer. Diabetes is almost bigger than cancer, but much attention is not given to it. Maybe because cancer has a times lifespan, whereas in the case of diabetes it is not time-bound, you can manage it still for a long time. I am from Nigeria, and I would prefer to stick to my African diet, but unfortunately when I want to do that all the time, I have to be careful to balance it with other diets that is healthier. We find the information provided very restrictive and an African does not naturally like to be restricted and we see ourselves as a stronger figure. (BALWD#19)

Most participants in the study expressed concerns not only about the prevalence of T2D among the communities but also about the complications and the problems of managing it for those who were already affected, as reported during the interview. Others attributed the growing magnitude of T2D in the communities to lack of adequate community awareness about T2D and community engagement with health intervention programmes. Therefore, people often live with T2D a long period without being aware, and when finally diagnosed, it

may then be difficult to treat and manage effectively. People end up having complications that could have been avoided if they had been diagnosed earlier. Two of the participants stated,

...because of too much information on the internet, people self-medicate with home remedies. It took me a long time before I finally went for a blood test. (BALWD#2)

You do not hear much about diabetes compared to the way you hear about cancer, obesity and other heart diseases. Yet, they keep saying this disease is prevalent among us African. There is less awareness in my community, I would say. (BALWD#15)

The risk of people having diabetes and related complications is very high (BALWD#21)

People delay seeking care and treatment early because of fear of the unknown ((BALWD#22)

Some other participants emphasised that the lack of government action and policy guidelines that are culturally sensitive on the prevention and management of T2D at both national and local levels were contributing factors to the growing magnitude of this disease among the Black African communities. Two of the participants stated,

The government needs to start changing how they deal with health conditions like diabetes, especially among the Black African community. There has been silenced intervention among the Black Africans communities. People do not talk about it

[intervention] because there is not much available to support our community. They.... I mean the government need to start talking about our diet and how to create more awareness through our local churches and Black communities. Many of us don't get aware of the healthiest condition until it becomes life-threatening and alarming (BALWD#7)

Diabetes is getting to a stage where the government need to act by providing guidelines and awareness on how to prevent diabetes and promote early diagnosis. I do not think I have heard much about diabetes in media except obesity as a risk factor. However, we do not really get obese in the African community. We do not suffer too much with the lower trunk; we have more of heavy bone compared to other ethnic groups. (BALWD#13)

On the other hand, the cultural transition to western lifestyle was reported as a major contribution to the prevalence of T2D among the Black African community.

We moved away from our traditional life, and we used to take berry and eat them straight away, now we buy berries in a packet from Tesco. We do not know how long they have been on the shelf and what preservative they have used to preserve it. Before we use to kill and eat that chicken, but now we buy chicken from Tesco and Sainsbury and doesn't look anything like a fresh chicken, it's white, it's been bleached, and you don't know what they have injected into the chicken. So, we've moved too far away from our traditional lifestyle to a western lifestyle and diet, we've got rice, bread, pasta diet and these things.... our body isn't used to digesting it, and we end up having diabetes. Finally, we have moved away from our climate, from our

farms. If we are in your original country, it makes a lot of difference in your diabetes.

(BALWD#24)

In contrast, one of the diabetes nurse interviewed, who has a Black African origin, described the prevalence of T2D as culturally oriented and alarming.

Within the Black African community, our diet.... People eat a lot of carbohydrates every time of the day and then there this joke in African where people say since they do not usually eat in the morning, they combine their meal together for lunch and eat more. Black Africans do not exercise that much because they usually have a routine of their daily work. One of the major issues within the Black community is ignorant. Sometimes they [BsSAs] know they should not do certain things, but they still do it. They will do all the walking, but still, have that big glass of milk and will loads of sugar in it. In recent years, it has increased, especially among the Black African communities and the money put aside to treat the diabetes patient has increased with time. (PRC1NU)

5.3. Health-seeking behaviours and lived experiences of the BsSA communities

This section describes the various self-management practices among Black Africans communities and the factors contribute to their health care-seeking behaviour. Many of the study participants with T2D were taking oral diabetes medications. Also, there is wide use of diet, herbal treatment, and other alternative remedies by the participants to manage their diabetes; most of the participants use these remedies regularly, and others use it occasionally. Two of the participants strictly use diet, and four participants strictly use insulin to manage their diabetes. Self-monitoring was also seen as an essential element of self-management.

5.3.1. Level of adherence to medication, diet regimen and physical activities

Under this sub-theme, information was constructed based on observed predisposing factors and barriers that influenced health-seeking behaviours of people with T2D and the type of services considered as effective. Participants understood that adherence to medical advice is essential for effective diabetes self-management. Many of the participants reported that medical advice was majorly centred on medication, diets and physical activities.

5.3.1.1. Perceptions about adherence to medication

The majority of the participants recognised the importance of adhering to medication. However, few of the participants with T2D reported that they do not adhere to treatment mainly because some of them are exclusively on a diet as a form of treatment for diabetes and others use alternative remedies only. The major reasons for adherence to medication treatment by some of the participants were accessibility and cost-free health care. Four of the participants stated,

The system in the UK is better, there is free access to clinics and can get your prescription easily. Although I find it difficult sometimes, adhering to my medication because I might forget. Therefore, what I normally do is, I set the alarm on my phone to remind me when it is time for me to take it. They make things easy for you here. They are trying their best, so I need to do my part as well by making sure I use my medication regularly. (BALWD#11)

The treatments are free and well medically controlled. Also, the clinics are more accessible, though you might need to book appointments. (BALWD#13)

I have an app on my phone now for online service; my GP gave me the link where I can actually place a request for my prescription. Therefore, I do not have to go to the clinic first to request my medication. All I need to do is just to get them from the pharmacy. (BALWD#22)

Your medication is free. You don't have to worry about spending money on tablets or injection. They are all free. Therefore, I use them, as I should. (BALWD#25)

However, while some of the participants described the need for their medication, many other participants reported not taking their medication regularly, despite no cost for treatment and free access to health care. In some cases, personal reasons and inappropriate changes to their treatment plan as a major reason for not taking their medications. Some of the participants felt that there was not much benefit in taking regular medications as they did not notice any difference or changes to their health

... It gets me worried when they change your medications and give you more to take. I get tired of taking them sometimes. (BALWD#14)

I do not take my medication every day. Sometimes you just assume you are feeling fine because you are not feeling any ill health. Sometimes you feel better, and you say to yourself.... I will take one tomorrow; I do not have to take it every day (BALWD#19)

Sometimes I do not take my medication regularly because I want to have a good sleep and some of them usually make you eat more. You know you get tired of these tablets. According to what they say about cholesterol tablets, it is good to take it continuously

and not to break it, but for me to have a sound sleep I sometimes do not take it. I do not bother to speak to the doctor because I do not want any more tablet (BALWD#20)

When you use too many of these medications, they can also lead to other illness you never asked for. It is difficult having to take 6-8 tablets a day. (BALWD#27)

Two of the participants reported that they had to skip doses because of the fear of going hypoglycaemic.

I feel so unwell sometimes at night after taking my evening tablet. Especially, in the middle of the night. Many times, I needed to wake up to get something to eat for me to feel better (BALWD#2)

I take my diabetes tablets twice a day, morning and evening, but sometimes I do not take my pills after dinner if I only had a small portion of food or did not eat well. I use another tablet for my arthritis, and this sometimes makes me not to feel hungry. Moreover, if I retake my medication to regulate my sugar level, that will be too much in my body, and I can become hypoglycaemic. Therefore, I do not regularly take some of them. (BALWD#15)

One of the participants reported the significance of stomach cleansing with natural remedies as a reason for not complying with medication.

I used quite a few other things; I do not just rely on medication, as the doctors want you to do. Most health conditions are caused by our stomach... by the guts and

harmful bacteria. When you get the balance wrong, you get all these health conditions, and when you get the balance right, you do not get the condition. Therefore, what I do is every four to six weeks, I do what I call colon to cleanse to remove the bacteria, so the good bacteria and the harmful bacteria and then I start to build more and more the good bacteria. Nothing to do with a tablet, just a natural powder. But you know that when we were children, whenever we go for holidays, our parent used to give us a washout... yeah, it cleans you out. They get rid of our bad bacteria or worms and get you ready for school, but we have stopped doing this, and we rely on doctors for tablets. Lemon, for example, is the most powerful drug, lemon cleanses you. You get a lemon and squeeze it in your mouth in the morning, and it gets rid of the bacteria as you swallow it. It cleanses your palate and your stomach and gets rid of too much acid. Moreover, this helps to bring down my sugar level down as well. If you just have tea without milk and sugar, it helps to bring your sugar level down. In Africa, our parent, when you get sick, what do they do? They boil the bush [herbs] and give you to drink, and it makes you get better. It saves you; you do not have to take aspirin or paracetamol. Therefore, that helps me keep my blood sugar level at the right level. (BALWD#24)

This participant further added,

It is too easy for the GP just to sign for a prescription but what you need is information, you need education. They need to give you more medication and education. Yes, that worries me because at the end of the day they are supposed to make you better. Moreover, people think the tablets make you better, but it is not; it only keeps you where it is. They are supposed to tell you if there are any other

alternatives to taking tablets. There is something called Kombucha, you grow it, and you drink it. It tastes, like bitter apple juice, but this puts good bacteria into our bodies and helps fight off high blood sugar level. (BALWD#24)

On the other hand, two participants shared the importance of seeking care and adhering to treatment regimens

Because I know that if I do not seek care or take my medication regularly, when you have diabetes, it can affect the different parts of your body... you know it can cause complications like heart problem, the circulation yeah. When your toes drop off and all sort you know your eyes... right now my eyes are no longer bright as they used to be. I still have my annual check, and then I went beginning in the year to have it done, but later about three months after that... they have started getting really blurry, and I thought probably I was eating things I shouldn't be eating. And I became really scared, so I phoned the optician because he says if I have any problem I should always come and see them, so I went there, but they tested me, I couldn't see things clearly anymore... they sent me for further test to check if I was developing any other thing. So, I went for the test, and they took the picture behind my eyes, but they said its fine apart from me developing a cataract. (BALWD#9)

Yes, I try to comply with my medication, and I see my doctor regularly because there are changes to everything, tablet, even information about your health. If you do not use your medicine daily as prescribed by your doctor, how would they know what next needs to be done or what else they need to give you if your health is not getting better? There is research going on so there will be changes and improvements in

medication they prescribe to their patients. Your doctor should keep you, and himself updated with these changes so as not to short-change you. There might be new things you can do better, so I try to see my doctor regularly and use my medication regularly. Right now, there is so much work to be done about diabetes treatment and finding a cure for it; we need to be seeing doctors regularly. (BALWD#12)

However, participants who are solely on oral medication and insulin dependent tend to adhere more to treatment than other non-insulin dependents. Three of the participants reported they needed to adhere to their medical treatment because of their health status and to avoid the risk of hypoglycaemia.

I have had seizures a few times in the last couple of years because I went hypo. This has made me insulin dependent. Therefore, I have no choice than to adhere to my medication and monitor my health closely. (BALWD#5)

I must take my two shots every day, one in the morning and one in the evening. I am always careful not to miss it. It is part of my life. (BALWD#21)

I guess if I do not adhere to my medication and treatment at this stage, I will be living in the hospital [laughing] (BALWD#25)

On the other hand, some of the participants delayed medical help because they considered the symptoms of diabetes as unavoidable.

The symptoms of diabetes are inevitable as they say... you will eventually have it
(BALWD#6)

*At first, I thought my lower backache was because of the sugar and beer that I take...
but later realised after my diagnosis that it was actually the symptoms of my diabetes.*
(BALWD#28)

Although many of the studied participants acknowledged the importance of adhering to treatment regimens, it is important to understand the reason why some of the participants did not adhere to their medication. This will further help to reduce other diabetes-related problem, improve health outcomes and provide a suitable regimen that can promote compliance.

5.3.1.2. Perceptions about adherence to a diet regimen

During the interviews with Black Africans with T2D, people's understanding of adhering to diet or diet restrictions was cutting down sugar intake and starchy food. Many participants adhere to a specific diet based on their health status, preferences, knowledge and other personal situations. Even more challenging is that fact that diabetes requires a lifelong commitment to a particular diet. Below is a selection of quotes from five participants who demonstrated this theme.

...well I try to follow strictly the diet plan recommended by my doctor. I no longer take anything that has sugar, I use honey instead. I take brown bread instead of white bread. I boil and grill my food instead of frying. I sometimes know [smiling] the taste

might not be as appealing as the way I would normally have prepared it to be, but I am more concerned about the content of the food and not just the taste. (BALWD#2)

... I have had diabetes for over 18years and one major thing that has helped me over the years is because I try to eat healthily. I specifically do not eat outside the food I cook at home. I love to prepare my own food because of that I do not eat what I did not cook, though there are exceptional cases in a social event or family function. I try to get whoever oversees the cooking at the event, making them aware of what I am able to eat. It is often not a major issue for me at family events. (BALWD#3)

My diet plan has really helped me to stay healthy. I don't have to rely so much on medication anymore. No more sugar. (BALWD#15)

I have been a vegetarian for years now because of my diabetes. (BALWD#22)

My doctor gave me a strict diet for months... because of my high risk of complications. I needed to be managed on a diet because of my previous experience as well (BALWD#25)

The knowledge of having to cut down carbohydrates and fats were predominant, but there were concerns about the measurement of calories and fat content. Few of the participants expressed concerns on how to calculate how many carbohydrates or fats contained in their traditional diet. There was considerable evidence of limited knowledge about the food composition of most African traditional diet. Two of the participants shared their views.

How do you measure the calories contained in fufu and Oha soup? This is just one out of many of my traditional foods. (BALWD#11)

The lists of foods they give you in the clinic are not applicable to a traditional diet. How do you want me to calculate the starch quantity of a cup of cassava? I usually wash my rice with salt before boiling it, and I still wash it off again before cooking it with other vegetables or spices. How do I measure the starch level at this point? (BALWD#19)

Eight of the participants were not much interested in sharing so much information why they don't adhere to the recommended dietary regimen. Based on the previous discussion with these participants, this was attributed to the lack self-efficacy, the uncertainty of health, reliance on oral medication and insulin injection. Below is a selection of quotes from five participants who demonstrated this theme through their experiences.

... I am much more concerned with monitoring my insulin intake than focusing on a diet. (BALWD#5)

Why would I want to restrict myself to a diet pattern because of diabetes? Even when you eat right, you still must live on medication anyway. Less worry, less problem. (BALWD#7)

I don't think I can ever get over diabetes. I live and do what I can at [sic] my own ability. So, I eat what everyone else eats, but I am also conscious of what it contains. (BALWD#14)

Taking my tablets is much easier for me than following a certain diet. I do not restrict myself to a diet because I use my medication regularly (BALWD#17)

...you feel tired of eating the same diet, knowing you have been taking the same diet for a long time and no improvement. (BALWD#20)

One of the participants, however, shared his experience of the difficulties in diet transition.

You can make simple changes to your diet because you get information from everywhere, Television, newspaper, doctors, and social media. You get different options for lifestyle. I have tried a bit, but it is difficult to balance it with cultural values. I have not changed my diet but only cut down a bit in terms of quantity and size. Exercise is quite good, but I can't do much because of my feet. I tried to keep doing things to keep my body active, but I can't do much.... Changing eating pattern is by choice, but I have not changed my diet completely. (BALWD#12)

However, this participant identified the need for robust research on African food.

A lot more research needs to be done about our cultural food because otherwise, Africans will just die as almost like a shadow... like you can only have this. You shouldn't stay off completely from the diet you should just know how to balance it (BALWD#12)

Two other participants acknowledged that changing the eating pattern and other lifestyles help them to manage their diabetes.

Yes, having a diet plan is very important for your health. But what I'm fighting though, is this thing... no matter how I try my best, in the morning I know according to my book your blood sugar should be 4-6 in the morning, and when I get up later in the morning, it reads 8 plus and then I begin to ask myself what I ate that increased the number. You know the liver stores excess sugar, and when you need sugar it pours it out, and it may pour out too much, so that means what you eat then sometimes doesn't determine how better you feel. (BALWD#9)

...since I decided to have a diet plan; I stopped drinking... I feel a lot better. (BALWD#21)

However, diet regimen for some of the participants meant eating healthy traditional diets or modifying diets to make it healthier and not diet restriction. Two of the participants stated:

No, not really. I still eat my pie, but I prepare it healthily, and I have cut out sugar. (BALWD#4)

I eat more green leafy vegetables and use less fatty oil to cook, like olive oil or sunflower oil. (BALWD#27)

Another two participant affirms this view,

..... I use honey instead of sugar, and I don't have anything fried. I try to stay away from fried food. I can still eat the same food, but I usually boil it or grill it. (BALWD#18)

Yes, I am trying to go back as far as I can think about the food that my grandparent eats, you know the green bananas in the morning not just in the evening, you know green bananas for breakfast and mackerel, and that keeps me going during the day. But if I had cereal, oats, or bread... no that is not proper food. And in the evening, you take yam and some vegetables. I try as much as to take my traditional food because that is what my body is used to and used to digesting it... If you are advised by your GP or a specialist, and they tell you that you've got to do that in your diet, what I try to do is listen to what they say, go away and research it myself and if it ticks all the boxes of what they've said, then I'll do. However, if I do research and it contradicts what they say, then I do not do it. I just tell them, you told me to do this and after researching, so and so said x y z, can you clarify? Is it going to do what you say it will do? My wife also supports me by making me much healthier food. We only eat out occasionally, not as often as before, and she uses good ingredients that are very healthy. (BALWD#24)

On the other hand, one of the participants reported that eating of sugary food and food high in carbohydrate makes one stronger and restriction can make someone go hypoglycaemic. This was identified in the following quotes:

I cannot eat sugar or anything high in carbohydrate because of diabetes, but then that is the first thing you look for to eat if your sugar level is too low. You need the strength. You just need to balance it and not stop it completely. (BALWD#6)

Lack of information from dieticians about Black African traditional food was also seen as a major factor for non-adherence to the diet regimen. One of the participants stated,

The nurses or dieticians, they refer you to, do not even know what you eat. 15 to 20 minutes' consultation time is not even enough for me to explain to the doctor what my traditional food contains or how I cook it. What I do is I try to reduce the quantity of what I eat, but not restricting myself to a diet. (BALWD#23)

One participant emphasised on the lack of awareness about Africans eating times and pattern, and how that affects health. He also described how cultural practices such as late eating routines and diet irregularity influence diabetes self-management.

Black African culture, we usually stay up late, and that often affects our eating pattern. Our usual time for dinner starts at 5 pm onwards and most times eat heavy food for dinner. When you eat a heavy meal full of carbohydrates and fats, your body finds it difficult to manage properly. You end up having too much excess of sugar, making your diabetes go worse. It is a cultural thing that it is time for dinner when the sunset, so following a food pattern or a diet plan might be a challenge. We end up eating at the wrong time. (BALWD#16)

Traditional food preferences and practices reflect the family tradition of African culture. Participants see these practices as unavoidable, and family expectations are to prepare delicacies that they believe have natural healing ingredients. When asked about traditional food preferences, three of the participants described their experience.

We actually do not put any restriction on a diet when it comes to a family meal. I try as much as possible to make everything on the table healthy to eat (BALWD#1)

I have to cook traditional meals for my husband and children, and many of the time eat from it because I'm probably too tired to make another meal that can be okay for my diabetes... or the cost of money and time preparing separate meal...that is why it's costly to manage diabetes. (BALWD#8)

I really prefer to use up my traditional food instead of shopping for processed food because I have confidence in the good nutrients contained in them. Many times I can't just avoid eating my traditional food, especially at family events and social gatherings. Many people will keep asking you questions if you decide not to join them to eat... they might see it as disrespect to our culture. I really do not mind taking oral diabetes medication later if I feel my sugar level has gone up because of what I ate. The African culture is really sweet and enjoyable when it comes to traditional food in social settings and again the way they prepare the food with African spices... there is this seed that looks like a bean; we call it 'Iru' or 'Sorghum bean'' that we put in vegetable soup, it is very good for the blood (BALWD#21)

On the other hand, few of the participants saw affordability as a major factor for not adhering to a diet plan. Four of the participants shared their opinion,

...it is expensive to stay on a dietary regimen. You might get your medication free, but the food they recommend for you is not free. (BALWD#10)

I tried to follow the diet plan my dietician gave me for few months, but I realise what I had spent on getting specific food is unbelievable. I could not afford it. The most important thing is to make sure you eat healthily. You cannot manage your diabetes alone with diet; you need to do exercise, use your medication. Therefore, I would not spend all my money on trying to adhere to a specific diet. (BALWD#13)

... staying healthy is expensive here in the UK, especially if you are on a low income. If you want to eat the best and a healthy diet, you need to have enough money. Again, not everyone can afford to be eating organic food all the time because they are even more expensive (BALWD#24)

They make your medication to be free, but then food is not free, some days I do have to eat what is available for me and what I can afford. (BALWD#26)

Although many the studied participants acknowledged the importance of adhering to the healthy diet, it is significant to understand the reason why some of the participants did not comply with a diet regime. Participants acknowledged the source of knowledge to families, friends and media.

5.3.2. Self-monitoring behaviour

A self-management task requires self-monitoring activities, incorporating diet plan, physical exercise, use of medication and blood glucose monitoring periodically. This could be an individual effort or supports from families and friends. Families and friends can provide warmth support and sympathetic acceptance of the health condition to encourage individuals to manage their diabetes effectively. Majority of the participants interviewed acknowledged that the importance of self-monitoring their diabetes. Five of the participants stated,

Since you only get one or two reviews every year, I try to monitor my diabetes myself to check if it is going up or coming down with my glucose strips. (BALWD#2)

I do the test on my own. I test my blood personally as often as I can. When I get up first thing in the morning, I want to see what it is and before I go to bed so that I don't have too low or high sugar level. Last night I went to bed, and I notice it was 6 point something, so I had to have a cup of tea and crackers quickly. Although it is not the right thing to do, I do not want to go hypo in the night, so I prefer it a little bit high. Although if you have it high for a long time, I was told that, it could also damage your kidneys. (BALWD#9)

Diabetes comes with associates as I always say it. So, I am totally on medication not just for diabetes, but cholesterol control; they put you on it as soon as you are diagnosed and tend to have blood pressure problem so if your blood pressure is raised slightly, they put you on the blood pressure tablet. So, I take different medication to manage diabetes and some other illness. I have a diet pattern, but personally, I do not restrict myself to diet if I take my medication. You should decide

on how you want to balance your life. I personally have developed a way of balancing myself out. I know when I have gone over; I know when I need to be strict with my insulin, tablet and myself on feeding. It is almost like clockwork. I can almost tell you what my blood sugar will look like without testing because I understand how I have managed myself for the day or the week. It is because I have had this for a while and I have gotten used to it (BALWD#12)

I check my glucose level in the morning and before going to bed. My brother, who is a medical doctor, brought me a glucometer. I use it all the time, and it really helps me to monitor my sugar level. (BALWD#15)

I take my medication on time... watch what I eat at the certain time of the day especially when going to bed. You know because you do not do anything when you sleep, your body is relaxed. If you eat anything before sleeping that could trigger your sugar level, you will notice the effect first thing in the morning. Therefore, I am always careful what I eat to sleep. (BALWD#19)

Every three months you have your blood sugar tested at the GP, they send it off, it comes back with an HbA1c, and this will measure your sugar level over that three-month period. That is the significant and actual way to check if you have your sugar level under control. Yes, on a day-to-day basis, you can prick your finger to get some indication of where you are in that period, but that does not give you a long-term view or perhaps how your body is disposing of the sugar. So, what I do every morning, I prick my finger and get an indication where I am, and that determines what do and what I eat throughout the day. Because if it is high, I have to do something to bring

the sugar level down. I need to do some exercise and working to bring down the sugar. Moreover, if it is low, I am going to pass out, so I need to eat properly today. Instead of me doing 30 press-ups, I will do 10. I scale down my activities for the day to keep that blood sugar level at a right level... It is being responsible for yourself [sic], taking charge of your health, keeping your blood sugar level under control... but also watching the food that you eat as well because you can use that to manage your diabetes. You manage your sugar level; you do not let it manage you
(BALWD#24)

Some of the participants did not rely on information from medical sources and HCPs and felt like the knowledge through internet sources are well updated and current. They felt the information they get from outside sources and the use of alternative remedies is enough for them to manage their health condition without the risk of complications. They reported using internet, books and learning new cooking techniques to improve their diet and other remedies. Three of the participants stated,

I am 58 years now, and I have had my diabetes for a long time. Not so much has changed from what your doctor tells us. It's still the same thing over and over again. Maybe a change of medication, but every other thing else is always the same.
(BALWD#11)

I manage my diabetes myself, and I do not just rely on information from doctors or nurses. The information they provide to you is too systematic and scientific.
(BALWD#23)

*I do not have to wait for my doctor to tell me what to eat or how to prepare it.
(BALWD#27)*

Family relationships have been found to be an important factor that influences self-monitoring behaviours. These were acknowledged by these participant quotes below.

My families are very supportive. My eldest child reminds me to take medication sometimes. He tells me... Mama has you taking your sweet today, I do not know why he calls my drug, sweet, but he knows I understand what he is talking about. I guess he realises I am not allowed to take any sweet kinds of stuff anymore. My family have been my support all these years. (BALWD#5)

*It has been very helpful having someone around you that can relate your condition. My sister-in-law is a diabetes nurse, and she has been useful in terms of providing me with information and advice on how I can effectively manage my health. I tried to do as much as I have been told in terms of what to eat and what simple exercise I can do.
(BALWD#17)*

In contrast, participants described the difficulty of monitoring diabetes around family gatherings. One of the participants reported infrequent glucose monitoring during a family event

I often struggle to monitor my glucose level properly during the festive period, when you have so many members of the family around there are kids everywhere, loads of activities going on. All, I am interested in at that moment is taking care of everyone

and making sure everyone is fine, I end up forgetting about myself. It is only when I start having some strange feeling that I get to check my sugar level. As an African woman, we have responsibilities of putting family first. It is our culture. You cannot help it. (BALWD#8)

Although self-monitoring was an important task in self-management practice, the anxiety of managing and taking medication appeared to be a major concern for some of the participants.

I do not like to talk about my diabetes sometimes; it really gets me frightened relying on medication to live. (BALWD#7)

The thoughts that you must do certain things at certain times is additional stress. This does not help to manage your health effectively. (BALWD#13)

... stress is unavoidable. I try to take my medication as often as I can... do some exercise, and I do that regularly, like jogging every Saturday and Sunday morning. But the stress of relying on medication never goes away. (BALWD#18)

... sometimes these medications make you feel vulnerable if you do not have them with you at some point. I remember I went for a baby dedication some time ago. I forgot to use my tablet before leaving the house. But immediately I remember, I could not risk waiting any longer, and I had to leave the event. I felt awful considering it was a family gathering. However, I was more concerned that anything could happen to me. It's an awful experience. (BALWD#22)

On the other hand, seven participants reported that the anxiety about the risk of complications and health deteriorating makes them take extra precaution while self-monitoring their diabetes

... sometimes the feelings I normally get on my fingers get me scared and worried.

(BALWD#1)

My eyesight is getting worse now, and that gets me worried. Therefore, I try to monitor my sugar level regularly. (BALWD#3)

I get very impatient and restless if I cannot have something to eat, not only because I know that I am blood glucose is quite low, but because I am scared that I might be going to go too low and can eventually pass out. (BALWD#6)

... I am always scared to go out during winter, especially when it snows because of the fear of falling. Your wounds will not heal up quickly, exposing you to further risk. Moreover, you do not want your legs amputated. (BALWD#10)

It can be quite scary when you have hypo, especially when no one is around to help. (BALWD#25)

When I listen to people, share their experience with complications, which makes me fuzzy and scared. Then, I think what next I need to do better or more. (BALWD#26)

In contrast, other participants, they were able to have control over the fear about diabetes, and they shared how they have been able to manage their diabetes

I do not think about it. I just live my life the way I thought I should. I prepare my food they way I should prepare it. Coping socially is not a problem. I have loads of friends, and they are always around. We have to get together and party. I take what I want when it comes to food. Sometimes I tell them I have diabetes and there are certain things I do not eat. There have been cases where I have been naughty, and I eat things I am not supposed to eat. This time I know, my blood sugar must have gone up, so when I got home, I took lots of water and took my tablet. (BALWD#9)

This participant further added,

I have so much to think about; I do not worry too much about diabetes and myself. As a Christian, I have a lot to prepare for daily, studying, meetings, so I do not really have much time to think about my diabetes. I work within what I can do for the day. (BALWD#9)

To support this view, one of the participants stated,

It is hard and sometimes confusing, but you have to take control and be positive. Many at times, I tell myself... I remind myself that I am doing a good job. You need to learn to encourage yourself. Even though you have people around you, it is still the world you live (BALWD#4)

In summary, for most of the participants, putting efforts into taking ownership and being responsible for own health is significant for a positive outcome. This could facilitate engagement in other self-management behaviours. Where there is a lack of confidence, this affects individual self-efficacy leading to poor health outcome

5.3.3. Self-denial/self-blaming - disclosure living with T2D

Participants described how they lived with their diabetes; some had to struggle to accept the diagnosis and others seem to prioritise another aspect of life. Many feel frustrated and angry about their diagnosis. For many, managing diabetes can be overwhelming particularly for those that had no prior family history of diabetes and those assumed to be living a healthy lifestyle.

I felt awful, really bad about it. Sometimes I even lock myself in the room. I remember when I was first diagnosed; I will lock myself in the room and cry my heart out... I felt bad and sad when I got to know I have it (BALWD#2)

I still struggle with accepting it. I ask myself why me? Even though we have some people in my family, that has it, but I still feel bad that unfortunately, I am one of those that unfortunately will have to live with it. (BALWD#8)

I felt dreadful...really dreadful when the doctor told me. After they had my blood test and she gave me the result, instead of walking straight home I walked all the way ...you know the consequences of what it can cause and then you have to be so careful, but you know after having knowledge about it you just live normally. But it is better you know than never knowing about it (BALWD#9)

First I was angry and then denial, I just don't want to accept it. I felt angry; I wanted to blame somebody responsible for it. Initially, I was troubled, I could not blame my mum, but she kept blaming herself because she was diabetes. I was almost blaming myself, and that was where the denial came in. (BALWD#12)

Diabetes is an on-going battle you can never win. That's just the way it feels like having to manage the illness on your own even when you get support from friends and family. (BALWD#17)

I was quite happy with myself and with what I eat before I was diagnosed, but I later became angry. They owe you responsible for your health; you become restricted to so many activities. I must be very careful not to hurt myself because diabetes will not allow your wound to heal up quickly. It is really upsetting. (BALWD#21)

No, not me... no no... I don't have diabetes, I've got people around me, I'm fit, I run around a lot, and I play football. No, you are in denial for quite some time. You think its old people that have diabetes or high sugar and not me. I am too young to have diabetes, you know I have a lot to do in life. What are they talking about? Yes, I was in denial for a long time, though they were honest with me that you know you have diabetes and you need to change your lifestyle, they want me to stop this, stop that, this is what you need to do and get on with it.... They tried to give me the gentle approach, but I'm like I've been doing what I'm supposed to do, I'm managing my food, but you say my sugar is going up... what's going on here? You know I did get a

bit concerned at one stage, tell me what is going on, and then I can know what I can do about it... I am like, tell me the truth. (BALWD#24)

I never thought I could ever have it; it was very demoralising (BALWD#27)

Some of the participants, however, seem to avoid thinking about the condition, prioritising other health condition and other situations of life over their diabetes. Seven of the participants shared their views.

I do not actually worry anymore. Worrying does not change anything anyways. (BALWD#3)

No, I just do not think too much about it. I just get on with it. (BALWD#4)

I have so many other things going on about the same time I was diagnosed with type 2 diabetes, so I cannot be focusing alone on diabetes. (BALWD#6)

Not at all, I don't think too much about it; you need to remember that you are not the only one going through it, so you need to deal with it. (BALWD#13)

Though it was a bit difficult for me at the beginning accepting it, I try as much as possible to stay positive now about it. At least it is not cancer. (BALWD#22)

I don't make a big deal out of it anymore. It is part of my life, and I have to control it. (BALWD#25)

One of the participants, however, discussed her ability to forgive herself for causing her diabetes, focusing on the importance of being flexible to manage other family responsibilities.

You cannot keep blaming yourself, that you are responsible, I needed to forgive myself for me to be able to manage my health effectively. I needed to be positive. Remember, you have other stuff you need to deal with. I have a husband and kids to take care. It is more painful seeing others taking care of you because you have refused to take up the responsibility. My kids mean a lot to me. In my culture, we put our kids before anything else. They are your future. I would not compromise any longer my kids' future because of my health. (BALWD#5)

When the participant was asked further if there were anything more she would like to say to help the researcher understand what it was like living with T2D and taking up family responsibility. She responded,

Many people do not understand, even your doctors, they do not understand the sort of depression that comes along with you having diabetes and having to manage it for life. Many times, negative emotions and thoughts come with it, but as I mentioned to you, my children keep me going and allow me to stay focused. (BALWD#5)

Another participant described her emotions as sometimes depressing.

Sometimes I just want to eat what I like, but I often can't, and that makes me feel bad... I get moody, and sometimes my attitude becomes offensive to others around me, especially when you go out with a friend. It can be frustrating and depressing sometimes when you can eat or drink what others are taking... because you've got diabetes. (BALWD#1)

Few participants considered diabetes to be inevitable and demonstrated defeatist belief towards modification of their lifestyle, and that their decisions, actions or lifestyle would not change their condition. Although, they recognised that some of their actions can reduce the risk of diabetes-related complications.

You only die once ... it is either your diabetes kills you or the medication you take to kill you. (BALWD#9)

You only live this life once and will die of something someday. Some people still live with their diabetes and live a normal life; eat what they want, so why should I worry so much because of what one doctor says to me.... We have this saying in my country, though in my language I will try to say it in English... you don't die of what you don't know... if I don't feel well, I take to rest, eat fruit and just leave the rest to God” (BALWD#23)

5.3.4. Balancing health with social life

One of the major challenge faced by the studied participants in self-managing their diabetes was balancing their health status with social life. With regards to managing diabetes,

participants appeared to have varying opinion and experiences about the concept of balancing their health with social life.

5.3.4.1. Impact on social identity – social stigma and discrimination

The perceived social stigma of living with diabetes was emotionally devastating and disengaging to many of the participants resulting in embarrassment and social disengagement. Participants described how they were reluctant to disclose their diabetic status and use of medication or insulin to their families and friends. Some participants found it difficult to take medication during social occasions while others use medication as a preventive measure to fully participate socially to avoid embarrassment. In other instances, however, participants see their T2D as a usual condition in society, and as such, they felt comfortable letting other family members and acquaintances know about their diabetes, without pausing to tell them further what they are not permitted to eat. Social perceptions about individuals being the cause of their diabetes appear to be one of the underlying foundations of the stigma surrounding T2D. Participants recalled worrying about the pressure of disclosing an illness to the family

Sometimes I feel very ashamed to go out, especially when you have to go out to visit a friend or go to another family's house for lunch or dinner. At times I just want to sit in my room... I don't want to go out; I don't want to feel pitied... I thought that is not gonna help me. Many times, I have to subject myself to medication or insulin injection before going out for a meal. If people are aware that you have diabetes, you might be blamed or looked down upon if they see you eating things that they feel might affect your sugar level... We don't take much about diabetes in my community, and people are in denial. (BALWD#2)

Once people see you are taking insulin, especially in my culture and community [sigh] they put on this sympathy look; people think you have a killable disease. Some might even start praying to God immediately that God should heal you and prevent you from dying.... it can be very embarrassing, so I would rather avoid making people aware of what is going on with my health (BALWD#5)

I do not go for health programme or recommended programmes by my GP... which I know that someone from my community might be attending. People tend to gossip a lot, especially when it must do with your health and I do not want anything that will make me uncomfortable or depressed with my illness..... I feel there is a lack of diabetes awareness in my community and I do not hear my doctor talk about this. People need to be aware that this is not a killer disease like some doctors and nurses portray it. I understand my culture, and I know how people see you... I only go to the clinic only if I need to get my medication (BALWD#14)

Where participants reported having families and friends around them, some hardly discussed their health condition with friends or families; there was an impression among some of the participants that speaking about the illness was not appropriate especially at social gatherings and participate in family events. As a result, they feel socially stigmatised as demonstrated in the views below.

No, diabetes is not something that you would like to discuss... with friends or families. You just don't talk about health issues like type 2 diabetes. (BALWD#7)

some things are more personal like your health that maybe you wouldn't want to share with others not affected by it, and that family member and friends might bring you down or blaming you for the traumas of your diabetes. (BALWD#18)

It sounds improper discussing your health in a social setting. You are meant to be having fun not making others feel responsible for your health or safety. (BALWD#22)

When we have family events, people organise for traditional diets or meal. If they are aware of your illness, you may or may not be invited because of that because they wouldn't change their meal because of you. It is respectful and honourable to eat together in family events, and you don't want to act or look different, so you keep your health status to yourself. (BALWD#25)

There is the huge social implication for one of the participants due to the loss of his eyesight because of his diabetes. He is officially blind, and this has stripped him of his independence, ability to drive and actively involved in social and family functions.

Before I was diagnosed with diabetes, I use to go out a lot with my friends. I used to do different sports and involved in different community activities, but as much as I still love to do them, I can no longer, because there are so many things I would have to depend on other people to do for me. I try to stay positive, not to feel handicapped, but the truth is I can no longer engage socially as much as I do before... years back. (BALWD#3)

Apart from social disengagement, family and friends' awareness of their illness was seen as a positive measure in supporting and improving self-management behaviours:

My wife is a medical doctor, and I have a close friend who is also a medical doctor, they always make sure I am on deck with the monitoring of my sugar and cholesterol level. My wife especially makes sure I eat most the meal she prepares at home; of course, she knows what I need to and needs not to eat. If we need to go out with a friend, we pick our food together and most times, she serves or asks for what both of us will eat... I sometimes find it funny, but it is just our culture for a woman to serve her husband's meal. (BALWD#6)

I told them immediately because they have to know. When you have a health problem, it is good that your family knows. Yeah, it might be embarrassing let people know in a social gathering that you have diabetes, but on second thought, it's a common illness, so you are not any different. (BALWD#9)

When asked if the participant was free to discuss health with other people apart from families or friends, she stated

It depends on who. I don't bother to tell anyone if there's no need to do. I try to go to the support group and helpful to some extent when you have other people there with the same complaint or maybe worse. So, I can discuss my experience with them because it also helps me to build my confidence. But when it comes to my communities, I don't discuss it (BALWD#9)

If they don't know you have it, how would they offer you help when you urgently need it? (BALWD#13)

Although social stigma was recognised as a major concern among the Black African community, some of the participants shared how they have been able to manage the situation.

It is a lot easier here than in Africa. Emotionally and mentally... I think I have dealt with that, you know... it is not like among the Black Africans where they see it as a stigma. I have lived here for a while, so I have tried to overcome that. Especially among the Black African communities, they stigmatised diabetes. People look at you in a funny way when they know you have diabetes. You should still be able to live normal like other people. I can discuss with anybody. The way people see you causes you to want to hide, and that is wrong, that is more pain killing people psychologically and make people not to be properly informed. (BALWD#12)

This participant further acknowledged stigma as 'a thing of the mind', which can be controlled.

It is a thing of the mind. When you think, you are not allowed to; it brings you into that seclusion. I go out for a meal with friends and family; it is a cultural thing among us that we eat together especially in social and family events. You only need to check your sugar straight away if you know you have exceeded some limit that day. I personally do not feel stigmatised because I know I'm not the only one that has it and people have become more aware of it now, so I don't feel stigmatised. (BALWD#12)

My health is important to me than focusing on what people feel or think. Especially, among the Black African gathering, you might be separated or not able to partake in a few activities, but... [sigh] you have to make sure you can control your mental health as well. Health is supposed to be complete, your physical health, your mental health and other areas of your life that you know if affected, and you will suffer for it. (BALWD#21)

On the other hand, some participants were unhappy with the service and identity they receive from HCPs. They feel they are being treated differently because of their cultural identity. Therefore, they find it difficult to socialise in African communities because of their condition.

I think it is a lack of understanding that allows people with diabetes and from an African community are discriminated. It is a cultural understanding of somebody's culture, particularly if you have diabetes, they see it as an African disease, and they ask you a series of questions that make you feel uncomfortable with your identity. I find that culturally offending and psychologically damaging. (BALWD#11)

It is difficult to think I have diabetes because I am an African. It makes you feel discriminated. (BALWD#16)

In contrast, some of the other participants do not feel stigmatised or worried about their diabetes. They did understand the awareness of T2D in society.

... It is a question of how long do you want to keep being hard on yourself because of what people would say or do? I don't worry anymore. The government is doing their best to create awareness. (BALWD#1)

I have no idea if anyone feels, somehow, being aware of my diabetes... it a common illness so I am not any different, and I should feel terribly bad about it. (BALWD#10)

I don't feel stigmatised because I know I am not the only one that has it and people have become more aware of it now, so I don't feel stigmatised. (BALWD#15)

I believe it is an individual state of mind and how long you have been diagnosed. I have been diagnosed for years, so I don't feel stigmatised anymore because I understand how society is now; they just bring out issues from nothing. (BALWD#20)

Oh, no... because I don't see my diabetes as discriminating. Everybody seems to be getting it, and the common denominator seems to be the food that we are eating. For us Africans, it is attributed to a certain food that we eat but more importantly lifestyle. The percentage of people overweight in the UK is very high. As I mentioned before, the weight around your tummy has a lot to do with our diabetes, and it is a societal issue.... Well, sometimes, you think you cannot drink, or you cannot eat a particular food in a place.... but what if you needed to eat it or drink it because you do not have enough sugar in your system. You should understand that no one had done this to me; I have done it to myself. You know.... my lifestyle at a particular time was not very good, and this has affected me a lot. However, many people have it, so I don't feel stigmatised. I'm very relaxed to talk to anyone about it (BALWD#24)

5.3.4.2. Collective social expectations and family dynamics

Social expectations and family dynamics were one of the sub-themes that emerged from the study as a significant influence on health-seeking behaviours. African families prepare meals, centrally, and care is sought within family knowledge. This could affect diabetes self-management negatively in a situation where the person preparing the meals is not knowledgeable or inclined to prepare food that is more suitable for someone with diabetes. Differing health beliefs regarding the causes of diabetes and expected treatment to affect self-management. Some of the participants shared their views.

The issue of you having a pattern of diet [sic] or a strict diet can cause a lot of family problems. I cannot say that because I have diabetes, everyone in my house must eat what I cook or what I prefer to eat... I need to be flexible.... I then end up eating what everyone else will eat. (BALWD#2)

You cannot just cook your own type of food for everyone to eat...you are the one that has the problem so why should you make other suffer along. (BALWD#14)

In African social event, it is cultural that you please your host by eating their food. You wouldn't say because you have diabetes, then they have to prepare your own type of food separately or you won't be eating at food, it sounds disrespectful when you must attend and eat in family events... so why not just stay at home? (BALWD#20)

According to some of the participants, peer pressure was another major challenge from social expectation. Even more challenging, people find it difficult to keep away from friends or family

More from family and friends, you can call it peer pressure; you want to do what your friends are doing. Young people tend to clutter and do the same things even when you know it might affect your health. For examples my friends were probably drinking and smoking, I initially was doing those things as a young man, but when I was diagnosed I became more sensitive, I joined them for a bit in denial but later found a walk myself out of it. Yes, there was a bit of influence from family and friends (BALWD#12)

Otherwise, it does not affect your lifestyle very much really, if you do not get pressure from friends, you know, with what you eat and drink. But I try to eat sensibly now whenever I go out with friends (BALWD#17)

In contrast, some of the participants did not see any major challenge to social expectation.

Everyone around seems very supportive, so, I try to adjust to other things I might find challenging to my lifestyle. (BALWD#8)

Well, it seems like, you know if I wake up in the morning, and the sugar level is very low, I make sure I have maybe some fruits with me, just in case the blood sugar levels go too low and if my sugar level is high, if anyone asks if I wanted a cup of tea, I said yes but black tea please as opposed to you having a glass of water or something else. You are constantly aware that you have diabetes. Moreover, it's actually you being aware of where you are at a particular time to actually make sure you try to manage it on a day-to-day basis. Yes, psychologically, it really affects, but socially I just try to manage it as best as I can throughout the day. (BALWD#24)

5.3.5.3. Gender role – family responsibility

In contrast to male participants, women with T2D described the feelings of being under pressure, managing their diabetes because of their responsibilities as either wives, mothers or sisters in the family.

Men do not have much stress compared to women. As an African woman, I have many responsibilities; I have in-law, siblings, husband and children to look after in the family. We [women]... keep many things to ourselves, we want to feel the pain alone, and you do not want your family to experience any difficulty because of your health issues. I think women need more attention because many die in silence, seek care very late.... Our roles as mothers make us stronger, but then, vulnerable, as many do not look after themselves (BALWD #8)

For some of the women, managing their diabetes appeared to be secondary to the everyday roles and responsibilities to their families. Some women interviewed reported on how their children helped in providing information and support related to their diet and ensure they take necessary medications for their diabetes at the appropriate time. They emphasised that the gender role of women in family contexts, in terms of caring for others as wives and mothers, can impede their capacity to care for themselves.

One of my daughters, who happens to be a nurse often, comes home with one health pamphlet of the other. The other one [second daughter] ... she knows my working hours and when I might be on break time... she will send me a message to remind me that it's time to eat or take my medication. I love them so much. They know I forget most of the time, even to eat, and when I get home from work, they hate seeing me

looking all stressed out and tired. So, they both try to make sure I look after myself as I would for them. My two sons do not bother so much about that... they say Mum is a strong woman (BALWD#16)

Household responsibility as a woman is enormous. You have to look after your husband, children, your husband's, your extended family... the strength of a woman looking after her family is incomparable. I most times forget I have diabetes. I am not saying men do not have responsibilities, but women are often under more pressure than men are. If you look at the rate at which people got sick and diagnosed with the disease, I am sure women always have the highest rate. (BALWD#19)

5.3.5. Challenges to seeking treatment services

Participants share the belief that Black African women have inadequate time for self-management because of family commitments and other social obligations. Although participants repeatedly revealed their awareness of self-care, some still express the feelings of uncertainty and frustration of medication and treatment given to them. Lack of motivation from HCPs due to their lack of interest in certain cultural beliefs and values were identified as a significant barrier to accepted practice. Limited time spent with doctors is seen as a major factor. The participants reflected on their past experiences with health care services and shared the following views,

Less attention has usually been given to diabetes compared to cancer, maybe because the lifespan of cancer is shorter compared to the longer lifespan of diabetes (BALWD#1)

Biomedical treatment is the commonly preferred treatment in healthcare because they are scientifically proven medication, but I have concerns regarding side effects compared to natural remedies. They just make you put all these chemicals in your body, and still, things don't get better. (BALWD#4)

Doctors see themselves as the only professional, and so they don't show much interest when you mention to them certain benefits of your traditional meals or religious belief (BALWD#8)

They say to you that medications are proven scientifically to be more effective compared to the use of alternative remedies. Many of these alternative remedies are natural remedies, so which other proof? This sometimes puts you away from using some of these oral medications because you know they are chemicals (BALWD#14)

Doctors just don't realise as an African woman; I have more responsibilities in the house. So many times, I don't even remember until later in the evening or when I feel really weak or tired... that's when I remember I haven't eaten or taken my medication. (BALWD#22)

They always expect you to do it yourself, but how do you do it when you are not sure of what to do with it... won't you rather just pray to God for healing and keep using whatever other healing remedies you have? (BALWD#26)

The advice and the professional languages used by HCPs and dissatisfaction with ‘patient’ centred service delivery was also seen as challenges to treatment services. Two of the participants stated,

The word ‘patient’... when doctors refer to you as a patient, I understand that’s what they call you when you are ill, but that medical word drives people away from going for treatment sometimes. No one likes to be called that name. They need to see you as a person, not a sufferer. I personally just don’t like it when I am being referred to as a patient. (BALWD#7)

Yes, I could say probably sometimes when, you know, you are talking to an expert or a GP, the language they may use is not the language... you know culturally, what I would use or understand. So, again, you have to be confident with yourself to ask them questions. I just say to myself, what are they are talking about. Perhaps you are taking what type of food they are asking you to eat. They use too much professional language that you don’t understand and sometimes confuse people from the Black African community. For example, when you measure the weight. People from the African communities have very heavy muscles, so, therefore, your average person would weigh more than someone from Europe because they muscle are bigger and stronger. Therefore, when they recommend specific diets to you, they are taking that from the European perspectives. The figures they get for people from the African community does not match what other measures they usually use to recommend treatments. (BALWD#24)

This participant further added,

I do, but I think sometimes the doctors, nurses, and GPs are too far removed culturally from someone from the Black African community. The language they speak, the measure and the criteria they use are foreign to us, and we may need to get a clearer interpretation of what they are saying. Especially when they talk about diet and the type of food to eat. There are a lot of people that walk away totally frustrated and do not understand a word the nurse or the GP is talking about. They just say your sugar is high and I need to stop taking sugar or starchy food. It's more than that, but they don't explain to you in a language that you will understand. Therefore you are unable to digest the information. (BALWD#24)

Another participant emphasised on the issue of the limited time for consultation with HCPs.

Doctors always have their meeting with you planned and structured. The 15 minutes they spend with you is not enough for you to discuss anything further within the limited time space given. I understand they might need to see other people for the day, but I still believe Doctors need to spend a good time with their patients to get more information on how they can best assist patients to improve their health. It should not be all treatment and medication all the time (BALWD#3)

One of the participants further expressed how the lack of time is a major challenge for an African man.

I personally do not attend all diabetes or health programmes. Though I have been referred to some of them, I don't attend them. I don't even bother to find out in detail the essence of the programme anyway. I am naturally an active person, and I am

quite aware of what I am supposed to do so I don't bother to attend them. Although if you want to describe an African black man, he is too busy chasing every other thing than going for the health programme. (BALWD#17)

5.4. The use of alternative remedies among the BsSAs for diabetes self-management

Factors relating to cultural values and health belief systems that influences T2D self-management behaviour include the prevalent use of traditional or alternative remedies, fear and mistrust of biomedical remedies, and fatalistic belief towards diabetes treatment. Traditional remedies were either used independently or used in combination with prescribed medications from HCPs. Participants described the diverse ways and methods through which they self-managed their diabetes needs in the UK. Most of the participants living with T2D relied on both the UK health system and alternative or traditional remedies, including herbs and foods to maintain their health and wellbeing. Some of the participants use these remedies regularly while others use them occasionally.

5.4.1 Cultural values of traditional medicine

Factors relating to cultural belief systems that influence self-management behaviours of people of Black African origin living with T2D include the use of non-biomedical remedies and traditional medicines which were seen as an 'alternative' to conventional medicines. These were expressed as trust in herbal remedies, which can be used independently or used in combination with prescribed medication, fear and mistrust of biomedical treatment, the affordability of natural remedies, the value of ancient remedies for disease treatment, and the trust and values in their 'traditional' meals. Social-cultural factors relating to the African

community, such as strong social support, heavy family obligations and peer pressure were also seen as influencing factors:

I believe in traditional remedies, and I know some of them works for diabetes... my mother has diabetes as well, and she usually uses bitter drinks and bitter kola, we Yoruba calls it Orogbo, she gets from Nigeria to manage her sugar level, so I use it as well. They are quite very bitter but I use it most of the time, it is all from natural source, and I have sincerely seen changes in the past months and has reduced the way I depend on medication. I only use my medication frequently when I really feel unwell. (BALWD#1)

I believe there are herbal medicines and natural remedies that can clear your diabetes without taking biomedical treatment, for example, some herbal tea and Aloe Vera can help lower your sugar level, so I take them regularly. They can be very bitter you know. When you have too much sweet in your body [laughing], you need something bitter to wash it off, don't you? There is a herbal leaf we use in my home country; we call it "ewuro" which English people might know bitter leaf. Anytime I travel home, I get them dried and bring them with me, or I can even go to some African shops to get the leaf because sometimes you can even use them to cook African soup. It helps to clean your blood from [sic] too much sugar. (BALWD#2)

Another participant also acknowledged a similar view on the use of herbal remedies:

You know doctors, many of them make you feel it is only the medication they give you that can work for your diabetes... we have this seed called "bitter kola", you can even

google it, it really works for diabetes, not only for diabetes but for even other sickness and they sell them in some African store. I take these seeds regularly, but sometimes I still take my metformin sometimes, but not regularly, maybe when I am not able to go to Africa or African stores where I can get some of these herbal seeds. I believe they do work for me, well you know diabetes is not curable, but at least I can try to manage it. Some people were able to manage theirs, so I believe I can manage mine.
(BALWD#8)

Three of the participants share their experience about how GPs make their diabetes treatment solely on medication, which sometimes leads to using alternative remedies because of the fear of diabetes-related complications.

Many times, I become too agitated to want to use medication because of the feeling like [sic] something is going wrong with my kidney or my heart or maybe a frequent headache. The information the doctors and nurses can be so scary and depressing, and you obviously don't want to have any complications with your diabetes, so as I am using the medicine they gave me from the hospital, I am also using some bitter drink to lower my sugar level (BALWD#4)

My diabetes depends on the medication, and I have to continue to use them even if I change my diet or lifestyle to avoid future complications. Sometimes I don't take the actual dose recommended, maybe instead of taking 3 tablets, I'll take 2, but I still take them anyway with some other alternative remedies to make me feel healthier and stronger (BALWD#5)

No... many GPs do not have that full knowledge about the values of traditional food and the health benefits. Although some [HCPs] are becoming constantly aware based on various researches on African food, they still have a long way to go. All they give you is medication (BALWD#13)

Three other participants also share their views about making other choices of treatment to complement biomedical treatment:

I use my own remedy as well as my medical medication... it is a mixture of herbs and green vegetables, which my wife usually does for me to help my diabetes. It actually helps to reduce my blood sugar level... it is a mixture of ginger, rosemary and pumpkin leaves. In fact, if you take it for continuously, it helps to slow down the way your blood absorbs sugar or ... glucose. It is a good remedy for diabetes. Honey and cinnamon are quite good as well for diabetes. (BALWD#11)

I basically used them the most time to complement my medication because I am insulin dependent (BALWD#12)

Yeah, doctors make you feel their treatment is the only thing that can help you manage your diabetes. Even if I do exercise or change my diet, the doctor told me I still must have been using my tablets. This gets really tiring sometimes, swallowing tablets all the time and you are still not getting better, so sometimes I use some of the green tea and cinnamon tea that my friend gave me. These are what our mothers use, and they even live longer than we do now. So instead of taking three tablets a day, sometimes I end up taking just one tablet.” (BALWD#16)

“I just don't like it when they tell you this is the only medication that can help you lower your sugar level when I know there's a lot of herbal remedies and traditional food that I can take to help me lower my blood sugar level. They just get you scared, don't they? I feel safer using natural remedies.... I use garlic, cinnamon and I eat lots of okra... it's very good for controlling your glucose level. One could live a longer, healthier life using natural remedies. (BALWD#22)

The majority of the participants that use traditional or alternative remedies often gets their advice on choice of treatment from family and friends who had experience of using home and traditional remedies for T2D or make decisions based on their own memories from their country of origin to decide on what remedies would be most effective. Many of the participants that use one form of alternative remedies or the other acknowledged support from families and friends. They also researched at the library, on the Internet or watching television medical segments to identify traditional/alternative remedies to treat T2D.

I decided to use herbal remedies because I found out on the internet and on herbal remedy channel that they are effective in managing sugar level. (BALWD#10)

Some of my family members and my friends who have the experience of using traditional and natural remedies to manage their diabetes has been supportive in sharing information. (BALWD#14)

My friend advised me to use a bitter lemon drink because it worked for her diabetes. (BALWD#18)

Our parents and grandparents live longer, and it is because of how they usually use traditional and herbal remedies to treat themselves. Before I came to the UK, I use herbs to manage my diabetes, and I still use it because it works for me (BALWD#26)

When one of the participants was further asked the reason for deciding to use alternative remedies, He stated,

I trusted in it and believed in it because I have grown in an environment and culture where people use it and recommend it to other people to use them. Family members also recommend it. I can also say peer pressure where friends advised you to use it because they have seen it work for other people. You really do not know exactly the side effect of these herbal remedies, but you just use them because of your belief in it. (BALWD#12)

However, the importance and the perceived effectiveness of their diabetes medication was also recognised:

Although I sometimes have a fear of side effects from the treatment, I still believe you wouldn't get this same kind of treatment and healthcare in Africa compared to what you are getting here. (BALWD#7)

For instance, if you go hypo, I think they call it... hypoglycaemia, yes, you are right, the doctors know what to do right away here in the UK because they have your record, they know you have diabetes. Even if you are a new patient, they check

everything they need to check first before placing you on any treatment. But in Africa, you really wouldn't want to be in that situation. The area I came from in Africa, when you have a seizure, it can be related to different things, not knowing that you just have low blood sugar. They can say you are evil or possessed with spiritual forces and they sometimes decide to give you some herbs before even taking you to the hospital. They can end up giving you treatment that could also complicate your problem.

(BALWD#15)

On the other hand, one participant shared her experience and concern with prescribed medication.

There was one problem I had, and I think it's when they start to change the medications. When they put me on the one, I can sleep well at night, it was metformin, it was doing all right, and I was doing exercise, so my blood sugar was fine. Anyway, later they put me on a cholesterol tablet, things became worse, and I could not sleep at night because my heart was beating too fast. So, I went back to them, I mean my GP, they tested me and said it's not normal. So, I was referred to a specialist to recheck me, and they said everything was fine, but I know it is the new tablet I am taking. I insisted that I was not happy with the way the new tablet was making me feel... anyway, I insisted they change me back to the one I was using before, and things got better. So later I got a letter saying that due to some circumstances, because of the price of the tablet they will be changing me since I think it was atorvastatin to Simvastatin because it's cheaper and so that was the one that caused my heart troubled and beating so hard. I could not sleep. So, they took me off because I insisted and they put me back on the old one. Although things weren't the way, it

used to be since they kept changing my medication. However, they put me now back on Pravastatin, which is a bit better. It is settled down, but some days it is not okay. They should have probably examined me properly before changing my medication. My major concern was that the changing of my medication has made me feel worse than before. So, I've decided to be using more of natural herbs, and that has improved my health. (BALWD#9)

The cultural belief that traditional and alternative remedies were efficient and useful instigated primarily from participants' conversations and relationships with family members and friends. Participants also reported that their family members and friends gained their cultural knowledge on the use of traditional or herbal remedies from their own experience with T2D and from their memories about treating other diseases from their countries of origin. The cultural belief about the use of African traditional medicines, folk medicine and the use of diets and herbs to treat T2D described the shared memory and experience of health and healing within the Black African communities. This cultural meaning and belief influenced participants' decisions to use traditional/alternative remedies as a complementary treatment for T2D.

5.4.2. Efficacy of Traditional/Alternative Remedies

Participants diagnosed with T2D believed that using traditional/alternative remedies could effectively control their blood glucose levels. Participants who use traditional/alternative remedies believed that they are not only able to efficiently control their T2D, but also manage other medical conditions that they have alongside diabetes, such as high blood pressure, high cholesterol and other complications like bad eyesight, and also provided holistic care. Thus, they often used a combination of traditional/alternative remedies to treat varieties of medical

conditions as well as their overall well-being. Herbal remedies were often used independently and in conjunction with oral diabetes medications to improve the quality of life. Although some of the participants believed that these traditional/alternative remedies were helpful in controlling their blood glucose levels and preventing complications from conventional medicine, they acknowledged that they only took them occasionally depending on the cost or availability of African stores and how the status of their health. Some of the participants mentioned that the bitterness of a drink could also be effective in lowering the sugar level in their blood and improving their overall health. Two of the participants stated,

Yes, I also use Aloe Vera and bitter lemon to lower my blood sugar... you know it is very bitter. You need something very better to help you reduce your sugar consumption in the body. (BALWD#2)

I take half a teaspoon of Aloe Vera every day, and that really helps in maintaining my sugar level... it is usually not too high anymore. (BALWD#13)

In most cases and I have experienced its effect on my diabetes, green bitter leaf and herbs, if you blend it and get the juice to drink, it helps in bringing down sugar level. (BALWD#19)

... herbal remedies help to clean your system; it detoxifies the body. (BALWD#23)

I use mine regularly, and it does help me a lot. I use garlic and bitter tea a lot to control my sugar level. (BALWD#24)

I use other remedies to prevent complications, no preservatives, no chemical or anything that can cause further damage to your health (BALWD#26)

Participants mentioned that the long history of the use of herbal remedies and plants remains significant in life expectancy and improving quality of life.

I take a lot of local medicine; you know all these medicines are what our grandparents used for [sic] their illness... even though they had this illness; they still live longer than most people this day. I drink boiled unripe fruits like banana, pineapple. This is what I grew up with, and it has really helped me. (BALWD#8)

Some herbs can help you to manage your diabetes properly, and you can use it for other illnesses, like, high blood pressure, body pain and many others. I have tried some, and I can see the changes in my health anytime I use it. (BALWD#10)

Yeah... I believe traditional, and natural remedies can be used to prevent and treat diabetes and other diseases. I use my medication when I need to use them, but I still feel the other natural remedies I used has helped over the years since I've been diagnosed with diabetes (BALWD#12)

Cinnamon (*Cinnamomum verum*) was frequently mentioned as an effective way to control blood glucose levels. Participants claimed to use it in its original stem form as well as in a powder and capsule form.

I used cinnamon tea, and sometimes I use the capsule because it helps to normalise my blood sugar level. (BALWD#11)

I occasionally drink cinnamon tea and honey to control my glucose level. (BALWD#18)

Although some of the participants were keen on the importance of the use of herbal and alternative remedies, some others mentioned the need to be careful with the use of other types of treatments.

I try to be careful of how much and often I take these herbs... you know they are not measured most time like the way your tablets are measured... so it won't cause further harm to me. (BALWD#1)

I use bitter leave, and pumpkin leaf "ugu"(pumpkin leaf), when mixed together and I drink the fluid from it, it helps me to balance my blood sugar to some extent. I know of, and I have heard of, but I haven't personally seen someone who has been fully cured with these remedies. I do know a couple of things that you can use that works in managing your diabetes but has not fully cured it. They do work efficiently in helping me manage diabetes. But then how much of that, can you take a day and how do you measure it? (BALWD#22)

Many of the participants viewed traditional herbs and the use of alternative remedies as complementary to their prescribed medication to satisfy their increased expectation of

comprehensive care. However, they also believe that the use of these remedies could eventually help them stay off the use of prescribed medications from their doctors.

If I keep using the herbs, I'm using now.... which I know it's working for me, I know I will soon stop taking my medication completely. (BALWD#7)

I only use two tablets now compared to what I have used before, I usually use 8-10 tablets together, but since I decided to use more of herbal remedies, I have been able to cut it down to just 2 tablets a day. It is a gradual process because I am looking forward to stopping it completely. (BALWD#14)

Whatever side effect I get from my medication, the organic and herbal medicine I take help to reduce or remove the toxicity of the medication. I feel a lot healthier when I use them to complement each other (BALWD#20)

One of the participants asserted that using both conventional medicine and other alternative remedies does not cause any further harm to her health.

The herbal remedies I use does not stop the use of the other medication, which I am taking now. I have tried them; still using them and the results have been good so far. I feel a lot better. (BALWD#9)

The majority of the participants that use other alternative remedies reported the significance to their health and general wellbeing. However, others who do not use herbal remedies for self-managing their diabetes express the fear of it causing more harm to their health.

I can only use it if my doctor recommends it. I do not use or put into my system what I do not know. It's not that I completely don't believe that it will work, but you are not even sure what quantity can cause damage to your health. (BALWD#3)

Though it is a thing of the mind if I don't trust it, I don't use it. I only use the ones I know might work for me, maybe I have read about the benefits of the internet or knew someone that had already used it. You don't want to cause any more harm than good to yourself. (BALWD#4)

Many people of African origin believe in traditional herbal medicine, but I don't. I use my medication often, and I pray to God. (BALWD#17)

In contrast, one of the participants was positive about the efficacy of traditional remedies based on his experience.

I don't just believe... I know because I am evident of it. I think I am one of those that have really gone down with the amount medications for diabetes instead of going up. For the last year, I have actually been taking fewer tablets through the GP with their acknowledgement. Yes, the green tea, the black tea, the ginger and the traditional food. All these things that I'm doing without medication are actually helping me manage my sugar level much more effectively than just with tablets, and I think it definitely feels like it's almost been ignored because alternative medicines or remedies cost you a lot, but it gives you a lot of benefits and makes you healthier. (BALWD#24)

The use of alternative remedies was also reported as effective in lowering high blood sugar level without causing any harm when used on a regular basis.

... yes, you have to take it regularly and continuously... that is when it becomes very effective and not harmful in any way. You cannot use it once and expect it to work straight away. It has to be the continuous use of it (BALWD#8)

I think they are safe without any harmful effects on your body. It helps to get rid of the extra blood sugar in the body and the bad feeling that might cause the disease to be worse... my religion encourages us to use it because it is safe. I think Reflexology is also good and safe because I have tried it before without any bad results or outcome and I don't think I have heard of anyone complaining about using it or causing more harm to their health (BALWD#28)

Many of the participants recognised the lack of unbiased information on the use of alternative remedies in the treatment of diabetes, which, if it were an individual's disposal, would enable them to make informed choices about care and treatment. They believed that policymakers and HCPs should conduct further research on the use of alternative remedies in the treatment and management of T2D to ensure safe and evidence-based practices.

Information about other alternative remedies should be made available and accessible to the public to reduce the irrational use of these remedies. (BALWD#16)

There should be more information from HCPs about other treatment one can use for managing your diabetes, other than just relying on medical treatments. I understand these medical treatments are free over here, but you should still have other choices. I'm sure other countries in Africa and even in Cuba; I learnt people have other choices of alternative and traditional medicine to manage diabetes. The government need to invest in this to improve the situation in the UK (BALWD#26)

The use of traditional and alternative remedies, however, did not conflict with some of the participants' use of the biomedical treatment for their T2D. Many incorporated their cultural beliefs about T2D into the biomedical model of treatment, as stated in the health belief model identified in the literature review (Chapter 2). Some of the participants expressed difficulty adhering to biomedical treatment alongside their self-management routine because of certain social and cultural elements of their daily lifestyle. Many of the participants strongly believed that the use of traditional and alternative remedies alongside other medical regimens would fasten the positive outcomes of T2D treatments and control their glucose levels.

5.4.3. Fear and Distrust of prescribed medication

Many of the study participants interviewed were taking prescribed medications such as Metformin and Pioglitazone, and two of the participants were on a strict regimen of insulin injections. Participants expressed their belief that oral medications or insulin injections are addictive and are regarded as a harmful chemical compound in the body compared to natural remedies which most used in one form or another. They shared concerns about the increased numbers of prescribed medications being added to their treatment regimens with little information provided to them. Information on medications was reported to be insufficient, as there were many brands of diabetes treatment medications being prescribed with no proper

and efficient regulation of the potential interactions or side effects of other medicines they were given by their doctors for users. Participants reported lack of information on alternative remedies and stated that policymakers should assist HCPs and service users in increased research, improved culturally sensitive programmes, and public health education.

I was only placed on just two metformin a day, and then it was increased to four by my doctor. I already have tablets to take for my high blood pressure, and then I was given aspirin to reduce muscle aches. So then, I had to take about 6-8 pills a day, and you ask yourself how long this will continue. I believe this will have a side effect on me on a long run because this will eventually get to a point where it becomes poisonous to my body. (BALWD#1)

My GP does not give me much information, as I want when changing my medication... Sometimes I feel they are just using me to experiment and would give feedbacks to manufacturing companies if the medication works or not. (BALWD#2)

Oral medications or insulin injections put chemicals into the body while natural remedies remove chemicals from the body. I feel like I'm close to death if I keep putting those chemicals into my body. (BALWD#10)

I have used prescribed medicines that really affected me, and I had to be rushed to A&E. I have also heard that many of this pharmaceutical company just make drugs to test out or... you know they use us as samples for research, and because the government want to save money, they will not even review you properly before they

place you on medication. They will just say this is good for you even when they know there will be a side effect or could lead to other complications. (BALWD#16)

When they prescribe me too many medications ... sometimes, you may have to take about 6 to 8 tablets. I refused to take them. I have heard that once you keep using the medicine and you rely so much on it, you have to take them every day for the rest of your life. That eventually becomes harmful to your body, in the long run, leading to other complications. (BALWD#19)

Some nurses have told me, I guess out of office ethics that I should not take too much medication if I am reacting to it and I should stick with my dietary restrictions. Why would they say that if they believe in what they give us? (BALWD#22)

I have stopped taking the Metformin prescribed to me because it makes me sick, so I only use traditional/alternative remedies to manage my glucose levels. (BALWD#23)

They tell you to try this and try that, but you are not guinea pigs or rabbit like the ones, they use in the lab. Why are they trying things on you? You should know which one works. Why should I be taking metformin for 20 years? If you have tried something for 20 years, you should ask yourself, hold on minutes, this is not working [laughing] but we still take the tablet every day. I need a cure I don't want you to hold me still to where I am. There must be a cure, there must be an alternative, and I cannot keep putting tablet and chemicals in my blood every time (BALWD #24)

Ever since I have been diagnosed with diabetes, I often go for the check-up, but I don't rely on the medication. You read a lot on the internet about the risk and the side effect of the medicine, and you ask yourself, why I would want to put myself at such risk when I can use natural treatments. As I said, I do go for the check when they sent me a letter, but I try to use more of natural treatment and diets that will improve my health than those chemical. I call them chemical. Do you know how many things they have added together, and they just tell you to swallow them? No [sign]. (BALWD#27)

When participants were asked whether their HCP was aware of their experience with these medications and the use of other remedies, many accepted that they never bother to disclose the use of alternative remedies to their doctors despite their standard prescribed medications. In most of the cases, the reasons for non-disclosure were fear of doctors or nurses discouraging them from using other remedies for treatment, short consultation time and lack of recognition for the use of alternative remedies in the treatment and management of diabetes.

Many of them [HCPs] don't believe in herbals and natural treatments. They don't care if it works... they would never recommend it (BALW#7)

Doctors are too busy to want to know if any, herbal remedies work... apart from those that you know come from either Africa or India and have the knowledge of these herbs... but they won't talk about it (BALW#11)

Some of the participants felt that the adverse effects of consumption fall within their own responsibility because of the lifestyle factors underpinning diabetes. Few of the participants

mentioned that they reported their experience with prescribed medication to their HCPs, which resulted in changing of medication, but others revealed it was a personal choice

Do you think they don't know what they are doing? They know the harm these chemicals and toxic substances are causing to your body. They know the side effects, and they know the values of natural remedies. But many of them will not recommend you to use natural remedies because of their profession. They rather will change your medication and ask you to try another one (BALW#3)

Yes, they are aware. I remember there was a time I went for a check-up, and I spoke to my doctor about a few things on my medication. I tell him, you know there are alternative in your country in India that we can use. She really felt uncomfortable but eventually, agree to it that there are plants that you could use to help you manage your diabetes, but you know she was very uncomfortable when I put her in that situation. (BALWD#24)

These findings revealed that participants' sense of trust and safety about the use of the natural remedies, mistrust of medical treatment toxicity and fear of negative reactions or dismissal from HCPs were significant concerns on the non-disclosure of using natural remedies. Moreover, insufficient knowledge regarding natural and alternative remedies on the part of the HCPs also contributed to this lack of disclosure.

5.4.4. Religious beliefs and spirituality

Religious beliefs and spirituality were other themes that emerged as an important aspect of the variation in how people with T2D self-manage their diabetes through alternative

remedies. Religious beliefs and spirituality seemed to play a major role in the lives of some of the participants in the aspects of coping with illness and decision-making. Participants' religious beliefs play a major role in their lifestyle decisions and view of health. The majority of the participants sees 'prayers' and 'faith' in God as an effective way of controlling their diabetes and providing support to deal with the emotional burden and frustration of the disease. The role of religious beliefs in participants' day-to-day living and diabetes management differs in their sense of hope for better health and different 'levels' of spiritual understanding. These 'levels' are based on the underlying notion that healing occurs at different spiritual levels, depending on knowledge, commitment and acceptance. Some of the participants recognised the relationship between the body and the spirit and the reflective values of this relationship. They recognised the importance of spiritual guidance through faith and prayers for a meaningful and sustaining life. Nevertheless, a number of the participants expressed fatalistic beliefs toward diabetes.

You cannot hide from your creator, can you? Unless you believe, no one created you. God made this body and gave the spirit. He knows what I am going through and what is happening to me, so he is my source of strength and my healer. Relying on God gives me hope even when medication fails (BALWD#2)

This is about faith... diseases are a test of your faith in God. God can test you differently, and there is always a reward if you can pass this test. And you can only do this by relying on God completely for your healing. Whatever treatment doctors give you is just to assist but not to give you complete health. (BALWD#7)

Everything that happens to one in life is for a reason. If something like diabetes is going to happen to you, nothing can stop it happening, though you might try your best to avoid it, it still doesn't matter how well you try... whether you control it with medication or not, it's going to come anyway. Do your part and leave the rest to God (BALWD#23)

Another participant reflected on her spiritual belief that God helps her to manage her general health effects.

I don't pray specifically because of my diabetes, but I pray for general wellbeing, physically, spiritually, mentally, emotionally and psychologically. Your doctor often does not even know how you feel apart from your physical well-being, so I always pray to God to be with me and take care of me in all areas. I'm from a Christian family, and I have been a praying woman all my life. I believe in God's word, and when you walk in that word and through that word, he takes care of you. I have the responsibility to eat right, do everything else I need to do as expected, but I rely on God for answers and complete health. (BALWD#16)

Few of the participants mentioned praying as part of their lifestyle, reducing the burden and frustration of managing diabetes.

I ask God daily to help me overcome the stress of my diabetes. I pray and fast a lot. (BALWD#1)

Prayer is my main key to strength [sic]. When you know... you do not have power over a thing, we have to rely on and trust in God to take us through the situation. Not us, not by what the doctor says or what you have read on the internet. We ask him for help and trust him that he will help us. I pray every morning when I wake up and before I go to bed and I believe that God grants whatever I ask of him [sic]. You have to be fervent in prayer as a lifestyle to keep going. (BALWD#3)

Praying is part of me, with or without diabetes. It is part of my life and helps me to have control over my diabetes and every other area of life. Doctors can provide you medication to help manage your health, but God's power supersede all medicine. (BALWD#8)

I would have died a long time if not for God. I know God looks out for me, so I always put my health and everything in his hands. I pray about everything. (BALWD#11)

Yes, I am a Christian, and to a very large extent, I believe in prayer, but at the same time, I am a realist. I try to do fasting sometimes because it really helps me to bring down my sugar level. And I pray to God to help me with my general health and just help me because I know I sometimes struggle with my diet... but he only can help me to live healthily. (BALWD#12)

Most times when I fast and pray, I always feel better with my diabetes. Although, it can be difficult sometimes when the fasting is long, especially during our Ramadan. But I believe Allah is always helping me and grant me extra strength. (BALWD#19)

One of the participants emphasised on how prayer helped her to regain her strength and helped her in her everyday lifestyle.

Most times as believers of Christ, you have acted with faith and believe in God's word of freedom from self. And when you submit yourself to accept it, the better for you. When you believe in God's word and talk to him in prayer, God gives you the strength and courage to stand the test of time and helps you go through that situation. God helps me and gives me the strength to accept the things that I cannot change. (BALWD#4)

Participants mentioned that prayer was a complementary treatment and not alternative medicine to control their T2D. Nonetheless, from participants' narrative demonstrating an in-depth understanding of religious beliefs, participants acknowledged the importance of taking personal responsibility and ownership for one's health in terms of diet and exercise to ensure complete wellbeing. Also, participants acknowledged the importance of health awareness and education at the local level through community and religious leaders.

I cannot be praying that God should heal me and restore my health when I still eat junk and fast food that I know affect my well-being, which is just a waste of time. I pray to God, but I still make sure I eat good food, do exercise and take my medication when I should. (BALWD5)

There is the saying that, 'God helps those who help themselves' [laughing]. I know God is a merciful God [smiling], but I need to also take sensible action by making sure I do what I'm expected to do. (BALWD#13)

Ill-health shouldn't only be viewed as a mistake you are being punished for, there is a need for awareness for people to understand that ...if you don't feel well or you feel very poorly, and that requires you to see the doctor, then you need to see them (BALWD#17)

God has the power to heal me completely, I know I cannot do his job for him, but I still have a responsibility to manage my health. You have to take back in your healing process by doing what is required. If it is ensuring that you take your medication regularly, you need to do it while trusting God to perfect your health (BALWD#21)

Two other participants shared their opinion on prayers not answered immediately.

Praying can help you with many things. The fact that you get your prayers answered for other things and you are not healed of your diabetes does not mean that God has not answered your prayer. It could just be a test of time, and it could also be that you are not even doing what is expected of you to do managing your health properly. (BALWD#6)

Some people are healed through prayers, and some others are not healed. It does not mean that you will not be healed if you pray. You can pray, but that doesn't mean that you will be cured immediately. It is with your faith in your prayers. Prayer is not the same as you are taking medical treatment. When you take medication, you expect the symptoms or feeling to get better, and if you do not feel better, you go back to see

your doctor... but prayers come with you believing in it. And the level of your belief depends on your relationship with God (BALWD#22)

On the other hand, one of the participants who use traditional remedies and diet to manage her diabetes reported that she still relies on God through prayers and having the belief that the remedies will work for her health. She stated,

You put everything in prayers. Even though I don't use medication to control my glucose level, I still put other remedies I use in prayer. (BALWD#10)

Three of the participants were convinced that their diabetes is curable with the combination of prayers, good diet, regular exercise and use of traditional/alternative remedies.

I am now looking forward to telling you soon that my diabetes has been entirely cured because I now use everything, I know can help me cure my diabetes [laughing]. (BALWD#14)

When I was diagnosed, the nurses told me that it diabetes is incurable, that I will have to continue to manage it. But I have faith that God can heal me and that he is going to treat me completely from diabetes. I know that I have a lot of work and commitment to do with my diet plan. I have a sweet tooth as they always say, I love to take sweet things, and then I'll later take my medication, but it's like you committing sin and praying later. I'm working on myself. (BALWD#18)

I do my exercise regularly, eat healthy diets, and I also take my medications, so I'm confident that with prayers, God will heal me and remove anything in me causing diabetes. (BALWD#25)

In contrast, one of the participants reported that religion does not play any role in their daily management of diabetes.

I am not a Christian or Muslim, so religious beliefs don't dictate how I should manage my health (BALWD#27)

In similar view that religion does not particularly influence treatment and management choices, two other participants who are Christians stated,

Not really... Practically, I am a Christian, I attend church regularly, but my religious life doesn't restrict me majorly from making the right choices for my health if that makes sense. (BALWD#15)

I'm a Christian, but I don't know the answer to that one. I don't... I think if you put strong belief in your religion in your way of life, it kind of makes you a stronger person and you are more positive to fight diabetes. It helps your state of mind. More psychological and spiritual than physical (BALWD#24)

Although few of the participants described 'spirituality' as not particularly attached to any tradition, but could have certain cultural values, many of the participants express a lifelong

interest in religious beliefs drawn from a range of spiritual traditions and life experiences. For example, one of the participants shared her opinion on spirituality.

It is part of our tradition. The tribe I am from in South Africa; we use oils, plants and herbs for treatment alongside prayers. They do not work in place of each other. The herbs and plants have their roles and prayer have its purpose. We need to pray for those herbs to work. We could pray on herb mixtures for days before being finally used on anyone that is sick. You need to attach some level of spirituality to what you use, for it to work. (BALWD#28)

One of the participants acknowledged that her level of spirituality has increased since she has been diagnosed with diabetes.

I pray more now and spiritually committed to the things of God. I have gone through difficult phases of life since I have been diagnosed with diabetes. And this has only taught me to be closer to God and be more prayerful (BALWD#26)

The religious belief and spirituality theme reflect the cultural belief that praying is an effective means for people to control their T2D and abilities to cope with the burden of the disease. Prayer and faith/trust in God give most of the participant's emotional and spiritual strength to cope with managing their T2D beyond the assistance of HCPs. They consider prayer and faith in God to be an essential complement to biomedical and traditional/alternative remedies for managing T2D and its difficulties. Even participants, who expressed frustration with the disease, fall back on their belief in God, hoping that their situation will improve or become tolerable on time.

A different understanding and beliefs regarding the causes and treatment of diabetes between HCPs and people with diabetes often lead to conflicting expectations between the two resulting in poor self-management behaviours, and consequently, poor disease outcomes. For instance, the belief that diabetes could have been caused by supernatural forces may undermine recommended medical care and treatment regimens as individuals may prefer to seek alternative solutions through herbal or spiritual means.

5.4.5. Concepts of Healing

Perceptions about care and healing of diabetes differ among the participants. Some of the participants acknowledged the differences between care and healing when using either medical treatments or alternative remedies.

It is the approach and belief in what you use as a treatment that helps your healing. I see no reason why people use a particular treatment, especially for your diabetes or any other ailment, and you do not put any element of belief in it. You have to help your body to heal. I don't use what I don't believe in... the doctor can only tell you what to do by providing you with the necessary care, but the healing process lies in you. The doctors only try their own knowledge and expertise to maintain your care, but... I am a Christian, and I don't rely on doctors to be healed. I use other alternative remedies and herbs to assist in the healing process. It is not just about diabetes; you have to be mentally, psychologically, spiritually and emotionally sound. Medications will not resolve all of that for you, and that's where your belief comes into place..... that is what helps my healing (BALWD#20)

You can be on medication for a long time and no major changes in your health. Since I've been taking herbal tea and this other leaf in powdered form... African Moringa, there have been changes in my blood sugar level. I feel more confident with my health... you know the feeling when you can see you are getting better (BALWD#23)

One of the participants sees the use of alternative remedies as a preventive measure for promoting healing:

I am very much open to using herbs or to seek alternative treatment as long as I have seen other people use it and it worked for them. I have tried a couple of herbs to detoxify excess sugar from my body... It does work for me... I could go days without taking medication... I feel more worried when I use medication compared to when I decide to put myself on a diet or use herbs. Sometimes all I need is just a simple therapy to relax my system (BALWD#8)

Another participant described her healing as incorporating the use of alternative remedies and beliefs into the everyday management of her diabetes.

Diabetes comes with a lot of commitment to your lifestyle, engagement with God. You have your spiritual life in one hand and medical realities on the other hand. It is working for me; I can reasonably live a life... I am happy, and I don't allow my diabetes to take the whole of me. My principle in life as always, been living for myself. I try as much as possible to go for massage therapy and this other one.... [Asking daughter] ... reflexology, yes that is it. It helps your body tissue feel relax, and you

know... it also helps in blood circulation. Even when you use medication, you still have to allow your body to make the medication work (BALWD#13)

The sensitivity and interpretation of healing are highly personal and subjective to the participants. In this account, participants, particularly engaged with the remedies they trust and believe improves their healing process. Some of the participants see their healing at both emotional, spiritual and physical level.

5.4.6. Contested perceptions about the use of alternative remedies

The knowledge about health and healing is often understood differently within the medical model. However, the knowledge underpins many healing systems of alternative treatments as a mutual principle for managing health and its responses holistically.

Perceptions and beliefs about the use of alternative remedies were understood as treatments provided outside mainstream medical care, providing a more ‘natural’ and ‘individualistic’ and ‘holistic’ approach, tailored to individual needs and overlapping with wider healthy lifestyle practices. There was a belief among few BALWD that specific alternative remedies rely on “placebo” effects and medical practitioners often contest their value. The majority of the participants living with T2D were mainly practical users of alternative remedies, with committed users and others sceptical toward conventional medicine. However, many of the HCPs express critical views on the use of alternative remedies, some directly challenging the toxicity and the composition of the remedies. However, few of the HCPs shared an openness to the use of certain treatments as part of broader beliefs in proactive healthy lifestyles.

We sometimes recommend the use of dietary supplements. We refer people to Osteopathy and chiropractic clinics within the NHS, especially those with arthritis or joint pain. These also help them in managing their diabetes ((HCP1Dr)

Some of the participants with T2D argued that diabetes goes beyond the current medical paradigm of the illness. Understanding the deeper level and connectedness of how views, beliefs and culture affect health were seen as paramount. The process of healing, from some of the study participants' perspective, means looking at a whole range of other factors in the individual's life: their attitudes, values, lifestyle, beliefs, and events that have meaning in their lives.

It is very important to understand the peoples' values and belief. You need to understand what they use outside what is recommended medically. Many doctors and nurses are not patient enough to understand that illness is beyond the body (BALWD#10)

However, four HCPs agreed that the holistic principle of certain remedies underpinned their practice, although they expressed it within the medical model. One of the HCPs expresses her thoughts accordingly:

You need to connect with the person mentally and emotionally to assist in the healing process. By doing that, I can establish the intuitive feelings of what matters to the individual when you recommend a particular regimen... It refers to that as a diagnosis per se, but we can say you are building a connection with the person's thought (HCP3Nu)

However, one of the nurses interviewed was very much cautious about using the principles of certain remedies for public knowledge.

It is something that you might know about, but you cannot use it in the medical profession. (HCP1Nu)

Some of the doctors interviewed argued that there is a lack of evidence around efficacy and effectiveness of many of the alternative remedies used by PLWD.

The body is a complex self-adjusting machine as we may say and could operate alongside other elements associated with it. The underlying idea as a health practitioner is that you are simply helping the body reach its maximum ability. Most times, we try to ignore these other elements as HCPs. We are very much concerned with evidence of practices accepted medically. (HCP2Dr)

I think there are many alternative remedies used for managing diabetes and has not been scientifically proven effective and efficient.... But some patient uses them, they trust them based on their beliefs and cultural values... not as recommended by their doctors. They seem happy to use them... but, the issues come back to the misuse of these remedies which could further lead to other complications (HCP4Dr)

However, one of the dieticians reflects on how certain diet regimens do not exclusively sit within the medical model.

... of course, food cannot be in isolation from the human body. It could be difficult sometimes to put people on the specific diet pattern... with my little cultural understanding and experience, it can be challenging to enforce a certain diet on people. It's a whole process of understanding the person as an individual... understanding the balance between the mind and the body, the environment and even the type of community the person is from... but so far, the medicine seems to focus more on the body composition when it comes to diabetes. (HCP1Dt)

On the other hand, for recognition of certain alternative medicine within the NHS,

We need to get evidence for its efficacy and efficiency and of course has to be carried out within the NHS system of healthcare (HCP3Dr)

The above perceptions demonstrate the contention on the use of alternative remedies within biomedical knowledge. People's subjective practice of healing based on the use of alternative remedies remains contended with the medical model. Biomedicine continues to exert a strong demand to control which remedies can be considered within the mainstream healthcare based evidence of efficacies and regularities.

5.5. Health care providers' (HCPs) engagement with cultural values and health beliefs of BsSAs living with T2D

5.5.1. Perceptions of HCPs about adherence to treatment and support system

Black Africans not attending clinic has regularly been a significant reason for late diagnosis and limited information. HCPs describe how this often affects continuity of care and lack of

access to useful information about the management of diabetes. Based on experience with Black African diagnosed with T2D, it was perceived by the HCPs that most Black Africans don't come back after diagnosis or keep to appointments. They come back only when they later feel at risk of complications or other health issues.

...they (BsSAs) are very poor at keeping appointments at the hospital. Out of all our patients with type 2 diabetes, the Black African are those that take a longer time to come back after their diagnosis, especially the men... some don't even come back. Well, they might have personal reasons, or maybe they think the information is not important because it is irrelevant to their own belief. It is very difficult sometimes, you know, trying to be on track with Black Africans when it comes to managing health (PRC2Dr)

Out of the many Black Africans diagnosed with type 2 diabetes in Nottingham, I probably only see one of two attend our programme (PRC1Nt)

Some of them don't come back after telling them about their diabetes. You only see them again months later if they realise they are not feeling any better or maybe they are now beginning to have other health issues (PRC3Nu)

On the other hand, one of the HCPs emphasised the individuality of diabetes treatment. Corresponding to the argument that attending a hospital appointment and adhering to treatment is an individual decision.

Treatment depends solely on the individual; we do not treat people as a group. Although we collectively say, they are a diabetic patient, but the therapy is individually based and person-centred (PRC1Nu)

Lack of continuity of treatment for a long period often results in having to start treatment over again to optimise care and effective diabetes control.

Most times, they default their appointment, and you don't see them for months or even a year. When you go back to their record, and you see the last time they had an appointment, then you ask yourself what has been happening to them. Some of them came back because of persistent infection or symptoms. They are treated as a new patient at that stage because we have to start a series of test and treatment all over again. (PRC1Dr)

However, from the Black African's perspective, the reasons why some of them do not keep to hospital appointments were anxiety, cultural values of natural and other alternative remedies, family commitments, and beliefs, lack of adequate information from HCPs and mistrust of biomedical treatments. Some have also decided to adhere strictly to diets and alternative remedies. Some of these reasons have been comprehensively discussed in previous sections.

In relation to the impact of medication prescribed on adherence, HCPs reported that people tend to feel unwell with the side effects compared to how bad they felt before with their diabetes.

Many of the treatments they often admit they stop taking are oral medications because of the side effect. And some tell you because of the side effect; they decide to go with natural remedies. Then... they later return when they have complications. (PRC2Dr)

With the medications that we prescribe to them, some come back feeling unwell and some, to inquire more information about the medication they have been given. Some often freely tell you that they have stopped taking their medication and some will tell you they will be stopping it if they do not feel any better. Some also requested that we change their medication or doses. For example, someone on Metformin might complain about sleepless night or very low sugar level. Depending on their current situation, we might change the medication for them or reduce the doses, but like I said it depend on the situation. There might need to do some other test to ascertain if there was no other health condition. We get these complaints all the time, but as I said, it depends on the individual health status. (PRC3Dr)

Well, I would say it depends majorly on the individual. You have some patients you treat, and you are very impressed and happy with them because they want to know more about their treatment. In fact, if you are not careful, they will tell you what they take and what they need to do to get themselves better. Then we come across some who don't want to live life anymore, who probably depression has set in, who probably is lacking one thing in the basic things of life like... I have nursed a patient who got divorced in the process and was losing his house. Obviously, he doesn't want to live life anymore, he wanted to kill himself, but I felt that was the road he was trying to take himself down through [sic]. But I have another one that knows how to take all her treatment; she knows how to manage her BMs [Boehringer Mannheim –

used for blood glucose test], and along the line, she was helping another friend who is diabetic, and they go for diabetes programmes together, she even agreed to help her friend with her injection because her friend couldn't do the injection. So, it depends on the individual; some have good knowledge, they have the information about the group they need to go to and what they need to do. Some know and have all the information at hand but will still refuse to do it or adhere to the information (PRC2Nu)

Some HCPs also reported that people lacked adequate explanation about the possible side effects of the medications and the expectations of diabetes control as a long-term measure.

If they have decided for whatever reason to stop their medication, whether you are not sure the reason why you are taking it, perhaps because of the side effect, then you need to speak to your nurse or your doctor. Many people don't bother to read the information leaflet for the medication (PRC1Dt)

Many discontinue their medication for one reason or the other, it could be personal, side effect or just lack of belief in the treatment ... without consulting their doctors. We obviously need the feedback to write our reports. There are discovery and researchers going on nationally about making treatment better for our patient, reducing the side effects. But when you do not use your medication as expected or you decided to stop using it, when we see you months later with another complication, it is often difficult to follow on from where we stop. We have to place you on the treatment again to control your diabetes (PRC3Nu)

Some of the medications prescribed and other treatment regimens are for long-term risk prevention, but due to lack of visibility, HCPs find it difficult to explain the need for regularity. The number of medications to be taken depends on the prophylactic management of their condition to ensure optimal diabetes control. It is also important that people are aware of the treatments and services available to them.

It is sometimes difficult to explain the prophylactic nature of certain medications to patients... such as Simvastatin to prevent the risk of complications, especially when you are treating risk factors. (PRC1Dr)

I would say it is not necessary, they go to the programme, but it is about making them aware of what service is available in their environment and having the information at hand. Some people they come here with the simplified condition of diabetes that they don't need to do anything and they give them basic information about diet and exercise. But sometimes, they may ask them to come back based on the information at hand. Therefore, it is a give and take, really. (PRC1Nu)

However, one participant living with T2D had wanted to see her GP, but was unable to do so because of the long waiting time:

"I don't like to go to the clinic, but I was turned down few appointments due to long waiting time unless if it is an emergency, but then they ask you to go to the A&E (BALWD#15)

On the other hand, one of the nurses argued that people do not have to come to the clinic for everything

For every diagnosis now under the NHS, we have the booklet, so depending on the individual condition, we have a booklet that simplifies all the basic information that the individual needs to know about his condition and the back of the booklet will provide groups and phone numbers they could contact. (PRC1Nu)

Inability to understand the connection between T2D and its related long-term complications was another major issue identified by HCPs for lack of adherence to treatment. HCPs described how most people from the Black African communities did not seem to believe that T2D could lead to other long-term risks such as stroke, heart diseases and total blindness since the pathological changes associated with these risks are often progressive, imperceptible and non-imminent

Many of these patients... when they come to the clinic, we provide them with most of the information they need, the basic ones to start with and also explain the risk of complications. It seems that the information you give them goes through one ear and goes out through the other ear. It has become a cultural thing, that they only come for treatment or any other diagnosis only if they have pains or have concerned symptoms they become worried about. They don't bother if there are no further symptoms, forgetting that some of the risks we tell them are progressive and may even be invisible for years, but build up and becomes a major issue later. (PRC3Dr)

5.5.2. Difficulties challenging culturally embedded health behaviours

Cultural identity was identified as fundamental to the outlook of life of people from the BsSA communities, and therefore, significantly influenced their health behaviours. In particular, the cultural importance of the relationship with family, cultural values and religion was

emphasised as influential on health behaviours. HCPs described how culture influences the way people from the BsSA communities understood diabetes and the related risks.

They put their family first; it is very cultural especially with Black African women. There is a strong cultural obligation to a Black African woman towards her family. I have seen a couple of them struggling to manage their diabetes because of psychological and physical demand... and this eventually affects their health (PRC2Nu)

I think many of the people from Black African communities are very religious and the more educated they are, the better they can manage their diabetes even with their religion. I have come across many that are educated and have vast knowledge about diabetes and medical treatments. (PRC1Dr)

Sometimes I feel less confident in what to expect when it comes to people's culture and belief. I feel less comfortable to challenge if I can use that word... challenge people's lifestyle when your medical profession differs from people's beliefs, expectation and values. You find yourself at the edge... and that can make them not be comfortable with you as a professional (PRC4Nu)

While discussing the cultural factors that influence health behaviours with the HCPs, many of the participants focused on Black Africans' culturally preferred traditional foods, which they described as mostly unhealthy for the people. Participants mentioned that BsSAs prefer eating food high in fat, starch, salt and high consumption of meat. All these foods were classified as lifelong traditional diet embedded in African culture and impeding on a healthy

lifestyle within the communities. The majority of the HCPs acknowledges that because many of these practices are deeply embedded in the culture, they are perceived as difficult to modify.

... I have seen people say their food is better than the medication we give them. They tell you, they have a particular way of cooking, they have a particular food they eat, they grew up with...and they find it difficult to adjust or admit any unhealthy. It is quite difficult and challenging because many of them never come back or attend any programme recommended to them when they think you are challenging their values or cultural identity. We deal with this all the time. (PRC1Nt)

However, some of the HCPs expressed that, although most Black Africans recognise that some of their traditional food becomes unhealthy if eaten inappropriately, they see traditional food as heartening and allows family coherence as an expression of their cultural identity.

Traditional food has a cultural meaning, and it is almost a spiritual symbol for some of them [people from the BsSA community]. When you tell them to change their diet, it is like you are taking the life out of them (PRC4Dr)

Explaining diabetes management to some of them [people from the BsSA community] can be very difficult because their diet is different from what you have in books and diet plans that we can recommend, and the cultural values are different...many don't understand the importance of most of the things that we [HCPs] say or recommend to them. They recognised more things that are related to family and their cultural values (PRC1Nu)

However, some of the HCPs reported feeling conflicted between their professions and uniting their medical knowledge around people's traditional food and lifestyle, and the consciousness of the fact that some of these traditional foods are unhealthy.

The fact that people know some of their traditional food is not the healthiest food, especially when they have diabetes, but still, choose to eat them... because of cultural values and beliefs is not the healthiest way of life. They have a strong family bond and beliefs around these foods, and it's usually difficult to challenge this as a medical professional. (PRC3Nu)

HCPs reported that there is the perception of people that HCPs are being judgmental, uncaring and lack the understanding of cultural values among family. Some of the participants (HCPs) recounted those patients often feel harshly judged on lifestyle than being helped.

I have seen cases where people emotionally break down when it comes to addressing unhealthy behaviours and diet. They sometimes feel judged, and they think we don't care about how they feel. (PRC2Dr)

Responses from the HCPs on the impact of culture revealed the reluctance of people from the BsSA communities accepting medical knowledge and association with cultural beliefs. However, some of the HCPs felt that this type of research gave them an opportunity to learn and understand some aspects of the cultures of the BsSA communities, which they believed, could have positive health outcomes especially for people living with T2D.

5.5.3. Professionalisation of support system – professional power in healthcare

'Professionalism' was one of the themes that emerged during the interview with the HCPs, and the recognition of medical knowledge was seen as crucial in diabetes management. Considering the significance of the support system for diabetes management, many the HCPs thought that it might be difficult for people who are culturally inclined to a particular diet to change their health behaviour without accepting the medical knowledge.

We have a good system in place where people should feel well supported. We provide professional support and help... and patients can talk to us anytime. However, they should also be able to accept the information we provide to them. They should trust us that we can provide them what they need to manage their diabetes (PRC3Dr)

People get themselves excluded from significant information... it does not matter what the belief is; this is about your health... your life. We are professionally trained to provide health support and care (PRC4Dr)

One of the nurses talked about the importance of remaining professional when advising PLWD as knowledge might conflict with cultures and beliefs

It is important that we remain professional in practice and not too emotionally attached to the patient's beliefs. There is the medium of listening to the patient to understand them better, but you have to remain professional in any advice and support you give them (PRC4Nu)

The levels of professionalism differ among the HCPs but reflect the extent of the various stages of health care provided to PLWD. The majority of the HCPs interviewed identified that these stages could sometimes affect the way people engage in their profession and accept support.

We have standards and regulations for each profession within the NHS. There are cases only doctors can provide diagnosis, nurses are to provide support and care for this diagnosis, and there are cases where the patient would have to be referred to another specialist for further management. I've also heard people say nurses are friendlier than we doctors [laughing] and I have heard people say their therapist are more relaxed with them than doctors because we get too professional with books and procedures [laughing] (PRC3Dr)

Some people see us [HCPs] as being too professional. I tell you, some people might have a problem they rather prefer to discuss with the nurses while some would prefer to talk to doctors than nurse because they see them as more professional (PRC4Dr)

However, some of the HCPs see no problem with the professionalisation of healthcare so long as they are holistic in their approach.

I think that the principle of listening to people is very okay as it improves your knowledge of people's lifestyle and culture. The fact that something doesn't have medical evidence doesn't necessarily mean it's not relevant to your profession. There are still debates on what counts as evidence in the mainstream, especially when is

culturally ingrained. I certainly do apply them (patient information) where it is relevant and when needed (PRC1Nt)

You often see yourself in situations where you think you have to get the information right. I should not say things that could affect my patient, trusting my profession (PRC2Nu)

When participants were asked whether there were any ideological conflicts between the use of medical treatment and alternative remedies and the implications for healthcare practice, one of the doctors interviewed refers to the definition of health, reflecting on the biomedical definition of health, the advancement in health technology and research, and evidence-based practice. Medical interventions and treatments have become the major tools to stop or reverse the disease process.

Yes... being healthy is more than the absence of diseases, but you need to be diagnosed to know if you are not healthy. You might prefer some remedies afterwards, but the place of diagnosis cannot be taken out. Medical advancement has created a lot of awareness on many diseases that alternative remedies will not discover (PRC3Dr)

The Dietician and Nutritionist interviewed were more reflective, as well as cautious of their profession.

I don't think we acknowledge other cultures well in the medical profession. We easily put forward our medical opinions, creating our recommendation on information at

hand, we assume this is what's happening.... but we can't always do that, we only understand the outside of what's happening to our clients but not the realities within the cultural setting they are from. I think that is where most of our clients [people with diabetes] lose out really and don't trust the information we provide to them (PRC1Dt)

One of the doctors, however, acknowledged that professionalism helps in managing the differing belief system among their patients.

But I think it is very difficult to say that the disease belief only has to do with your culture. People come from different cultures, have different beliefs, and I believe they have different disease model and diet pattern. I think I would be more challenged to understand these cultures differently or empathise with the belief systems that are different from my belief systems as a medical professional. Therefore, I don't think you can equate professionalism with people's experience or their knowledge (PRC1Dr)

One of the nurses interviewed, however, acknowledged the need for more fluidity when it comes to medical professionals accepting people's cultural knowledge.

... If there were some significant values discovered in people's culture, these things are essential, and you need to be aware of them as professionals. You might think it is too simple or complex but can be very helping to provide appropriate support and care to people (PRC2Nu)

Although there was uncertainty about the desire for an application of cultural knowledge on continuing experience of professionalism, some of the HCPs acknowledged the significance of a knowledge-based approach to diabetes care. Some of the HCPs identified where their different knowledge of cultural issues on health behaviours and cultural expectations of PLWD had been helpful in their profession.

Knowledge about people's cultural expectations or the way they relate to health decisions helps you a lot on how to manage them. Black African men are not the easiest to deal with [laughing] when it comes to health behaviours... but as I said earlier, understanding some aspect of their beliefs, culture and expectations could assist you in the process of you providing care for them (PRC3Nu)

However, uncertainty remained where HCPs established that stereotypical knowledge about Black African culture and impact on health behaviours does not apply to all BsSAs living with diabetes. Some of the HCPs reported exploring further the cultural issue with their patients.

Instead of you thinking this person is from this culture or belief system you need to treat them as a person. It enables you to see beyond their illness (Prc1Nu)

5.5.4. Conflict of cultural perspective: lack of culturally sensitive information

A lack of cultural and religious beliefs, awareness by HCPs when making referrals and recommending diets was identified as a major challenge to accepting certain health care services. Participants with T2D (BsSAs) narrate a negative experience that has prevented them from accessing certain health services.

The diet plan and nutritional handbook... they don't include any of traditional meal apart from rice. How do you want to calculate the calorie intake or the full nutritional content of a bowl of yam flour and some of my traditional soup? [Laughing] I understand this might be too much for doctors to have all this information, but then how can they help me when they do not know what I eat. (BALWD#2)

I was referred to a slimming centre to assist my weight management. But going there for the very first time and being a Muslim, I was very uncomfortable seeing people drinking at the bar and some women dressed inappropriately. This puts me off, and I never went there again. I wanted to tell my doctor the next time I saw her, but I just thought maybe she doesn't even know where the place is not to talk about knowing what is done there. She was probably given the flyers to give out to her patients. They [HCPs] need to consider people's culture and beliefs before being referred because if it doesn't go with your belief, then you wouldn't turn up for the programme. (BALWD#11)

Most of these HCPs are not sensitive to your culture or values... because they are not very well informed and they only act by the books [sic]... no, because they don't have enough time to spend with you, you are only assigned just 15minutes review with your doctor to allow other their appointments as well. (BALWD#12)

When participants with T2D were asked if they could respond well to treatment and management advice given by a professional if services incorporate people's cultural values and beliefs, many of the participants were subjective about their opinion.

Yes, but the HCPs are not interested in your culture or beliefs. They might have a belief or culture that is very different from yours. The truth is I never rely on doctors. I go ahead to pray about it and if I need it... then I take it. I don't worry about it or allow it to bother me, so I just do what I needed to do. I rely on God for direction (BALWD#8)

My GP is a Pakistani doctor, he understands my cultural values and needs to some extent, the Doctor recognises some of our African diets because they are also very cultural in their home country so that he can relate to me very well sometimes. But the fact is he still has to act based on the structured information and procedures he's got in his book. And most of the English nurses, they don't have information about our cultural needs, they just tell you this is what you need to use, and you need to take them. People get depressed, and their diabetes weighs them down more when you tell them to stop eating a certain diet and restricted to a particular diet, it often feels like they are taking your cultural values away from you (BALWD#24)

In contrast, HCPs reported that fatalistic beliefs and religious beliefs towards diabetes make most people from Black African communities resign to the sense of powerlessness.

I think sometimes the response to self-management varies depending on the individual, but quite frequently, people get scared and afraid of what could happen to them over time. We give them all the information they need and refer them to other supports. For those having low self-efficacy, we provide the right support. However, a

certain amount of hopelessness and loss of control makes people lack the confidence of being able to manage their diabetes (PRC2Nu)

Another participant (HCPs) reported that cultural beliefs about health contribute to people not being proactive in terms of diabetes self-management regardless of the information provided, which could have a negative impact on their diabetes treatment:

There are a lot of cultural barriers to the understanding of diabetes as an illness and beliefs about the efficacy of the medication prescribed, especially among people from the African and Asian communities. This makes it more difficult and challenging because of their cultural beliefs, so even when you provide all the necessary information needed to improve their health, they still don't understand or accept it (PRC4Nu)

However, some of the HCPs reported that people's religious beliefs also help in building self-confidence and being positive over having control of health.

Many of the patients tell you, sometimes how they have been able to overcome the stress of diabetes through prayers, fasting and relying on God for help in coping with their diabetes (PRC2Dr)

With their faith, some of the patients can take up the responsibilities of accepting and adhering to the treatment or diet plans and support we provide to them (PRC1Dt)

We get referrals most times and when they come around... many of them tell you about their beliefs and what could work well with them based on their belief. We try as much as possible to understand them... well I try my possible best to listen to them because that's the only way you can gain their trust and build their confidence in managing their health effectively (PRC1Nt)

You need to work with them understanding their beliefs and approach to life. If you are recommending a treatment based on just what you have in the book, I don't think one is doing a good job. Beliefs are important. They help build self-confidence and people being positive that they can effectively manage their health. (PRC3Dr)

One participant (HCPs) felt perhaps changes to cultural practice in terms of management behaviours need to be gradual and HCPs should be more sensitive to some of these issues to improve the quality of care provided to them.

Well, if you look at some of the African cultures... you have to remember there are different cultures that appreciate family relationships through diet. They usually cook largely for families, so if they are going to change their diet pattern, then that might affect their relationship with their family. Sometimes we need to put this into consideration when recommending diet changes (PRC1Nu)

On the other hand, two participants felt that the use of medical terminology to explain the condition might conflict with certain beliefs and culture and lead to a further misconception of the illness. Some of the participants with T2D (BsSAs) identified the need for practitioners to engage at the appropriate level of understanding.

It is about understanding my belief as well. Doctors and nurses need to learn to understand one's belief. You cannot just say African meal is not healthy enough or say they are bad for diabetes... you to need to make me understand in lay terms what I need to do. (BALWD#21)

One of the HCPs supported this view. She said:

Because if they [BsSAs living with T2D] don't understand, they can't go with you, it's a journey; it's not just giving a diagnosis and sending the patient away, it commits the patient to a lifetime regular health check. So, they need to go through that journey understanding every step of the way. That is the importance of the education right from the beginning, so they can understand why they do everything they do through the journey of treatment. (PRC1Dr)

Difficulties with diabetes self-management due to cultural norms and beliefs were generally identified by healthcare to be major challenges resulting in poor health outcomes among BsSA communities. Identified the cultural norm for women to remain within and care for the home and family as a major barrier to exercise.

5.5.5. The issue of disempowerment and ambiguity.

One of the challenges that emerged from a discussion on HCPs' engagement with people's cultural beliefs was disempowerment and uncertainty, on the part of the HCPs. Some of the HCPs reported that they are often disempowered when it comes to cross-cultural

communications within a medical approach, resulting in complexity in diabetes care. There were concerns about approaching patients about beliefs, practices and values.

Sometimes, you get so afraid of offending people or say something contrary to their belief. You then become very sensitive about what to say and what not to say to people. We become too careful... and that's what creates the barrier to actual communication with the patient (PRC2Dr)

There are different cultures you come across when working with patients and they are commonly ingrained in various beliefs... the feelings and knowledge are certainly different for each patient in my everyday experience with people from the Black minority groups... you haven't got the same sense of feeling of what the belief could or should be. You just have to prepare yourself for each as they come (PRC3Dr)

Yeah, different kinds of cultural beliefs and then you get anxious about getting things done in the right way. You don't want to assume your knowledge is applicable for all. You have to think of how to progress with each of the patients, and that creates much stress. (PRC1Dt)

... yeah, as a health professional, we get training on cultural diversity and cultural competence...some situations can be quite difficult to handle by just asking questions and...you really become disempowered to progress with the patient (PRC2Nu)

... I remember there was a time I was talking to a patient about the food he needs to start eating, gave her some examples of food I thought they eat... and then he

responded to me that he's not a Jamaican, you could see how furious the look on his face. I became confused because the patient information reads Black African and I just thought they are all the same. That was really the end of the discussion about food because I became aware that this man's cultural diet is definitely not part of the information I had at hand (PRC1Nt)

... It just makes you feel so helpless, doesn't it? You wonder what else is left for you to know...you come across many things in different ways, at different times with different people (PRC3Nu)

I think naturally some people chose to speak to doctors and nurses from the same ethnic background as themselves... I can see it in some patient, especially when they've met one before you... they want either a black doctor or nurse whom they are much more comfortable to talk to [sic]. I wouldn't think it was a racial thing, but they just prefer to talk to someone that they think would understand them better (PRC4Dr)

However, some of the HCPs feel very uncomfortable with their low level of cultural knowledge, and some felt that this uncertainty affects the quality of care provided to people with diabetes among the Black sub-Saharan communities. A few of the HCPs were concerned about limited communication with patients that shared different cultural beliefs and values. Nevertheless, two of the HCPs – nurses, expressed a different view about cultural awareness not being perceived as important within their professional roles. For example, they described their roles as being responsible for doing routine checks for people living with T2D, for which they did not need to be aware of any cultural issues.

... the problem is more about the vague information we receive about people's culture. When you are not properly informed, it doesn't make your job easier for you (PRC2Dr)

... I don't know, my role [nurse] doesn't require or demand much information about people's culture... and perhaps we need something different that can assist HCPs to be more culturally informed (PRC4Nu)

The emphasis on the lack of cultural knowledge and disempowerment partly reflect the dominance of the medical model on diabetes care and the reliance on expert knowledge as the main source of information within the conventional healthcare system.

5.5.6. Poor level of information provided by HCPs

Participants (BsSAs) described the role of HCPs in supporting their diabetes management is limited to majorly prescribing medication and providing information for next routine check-up. Some of the participants (BsSAs) also reported a poor level of information about cultural diet for diabetes. For example, one participant said:

Anytime I go for a check-up with my GP, they don't do anything else than to prescribe medication. I hardly go to the GP anymore unless if I don't feel well or I need to get my flu jab, sometimes I just call the surgery to check when to pick up my prescription. (BALWD#1)

They don't explain anything to you... they have the system where they read and review everything themselves. They have just 15min to spend with you anyway, so no

time to be explaining things in detail or asking you in detail how you have felt with your last prescription. (BALWD#7)

I still don't understand why most nurses and doctors don't know much about the food we eat... The nurses should be able to give more information on how to measure food especially our traditional food. Food that I can eat and what is contained in it... tell me more about what could go wrong if I continue to eat the food regularly, how they can help me take better care of diabetes, and not just talking about medication. (BALWD#14)

In the same way, another participant (BsSA) thought that the general practitioners are too vague in their approach to sharing information, which invariably does not make the reason for complying with medication or screening so clear:

The doctors and nurses are sometimes quite vague in referring people for screening or programmes that they think could support your wellbeing.... I get confused with some of the programmes they recommend. Even when you asked them a question, they just tell you that's what is prescribed under the NHS (BALWD#3).

The information they give to you sometimes can be very confusing. Why should I be given leaflet for a slimming course to reduce my weight when I am not even overweight? (BALWD#13).

Although the participants living with T2D are routinely referred, some participants (BsSAs) thought that the HCPs needed to provide more information on reasons for attending the

sessions or courses recommended and the benefits. Two of the (HCPs) stated several instances where some people did not understand the reasons for attending recommended sessions.

Some of them don't even know why they have been referred to the juggling programme. You see them once, and you never see them again (PRC1Nt).

The doctors and nurses shouldn't leave it to us to explain why people living with diabetes should be attending the session. They need to explain to them at the point of diagnosis. Spend some time to explain the importance of the sessions. People don't really understand the importance, and that is why they don't fully participate (PRC1Dt).

Some of the participants (BsSAs) confirmed how they searched for additional information related to diet and specific disease progressions themselves or asked family members and friends about any other information they are not clear about. The participants (BsSAs) also expressed that their families most times have limited knowledge about the disease, the risk factors and their need to comply with a particular pattern of diet, so there is little help they can offer them:

Sometimes I don't think my family and friends understand the truth that if I don't manage my diabetes properly, I could be on insulin for the rest of my life and it could lead to other complications... and they think I'm taking my condition too seriously by being too concerned about what I need to eat or not to eat. My husband uses this word... that I'm too scientific with my health, you know, it's all about what science

and that's what your doctor tells you... yeah, exactly, he does not understand fully what could go wrong if I don't manage my diabetes. (BALWD#5)

Some of the participants (BsSAs), however, commented that having information and health awareness for people that are at risk of developing diabetes and their families would have been helpful more in helping more people have control over their diabetes:

Well, I guess, when more information and awareness are given out there to the public... it's like the way cancer, and HIV awareness is out there through all channels and medium where the whole public will in one way or the other access it. It would be helpful for diabetes awareness as well... for everybody to come to the knowledge of the risk and preventive measures... including your family... that way everyone is informed of what diabetes is and what could go wrong if not managed effectively. We shouldn't wait until we get to the hospital before we know what diabetes is and what it could lead to... you hear about cancer everywhere. (BALWD#8)

When the participants (BsSAs) were asked about the role of doctors and nurses in providing information about diabetes management, some of the participants stated:

... I see my doctor regularly because there are changes to everything, tablet, even information. There is research going on so there will be changes and improvement. Your doctor has to keep you and himself updated with these changes so as not to short-change you. There might be new things you can do better, so I try to see my doctor regularly. Right now, there is so much work to be done with regards to

diabetes treatment and finding a cure for it; we need to be seeing doctors regularly to get an update (BALWD#9)

The healthcare system is quite too theoretical... the first thing they do is they open their book; it's like a manual they have to go through knowing that whatever I complain about may trigger something else. Their response is more too theoretical, and it is possible that people can be misdiagnosed. There might be instances where it is not what the book says it could be something else. There are cases whereby they ask you to go for the further test, but we are talking about you being in this process for weeks or months before being finally diagnosed or probably just tell you there is nothing else. This only makes one panic (BALWD#12)

They [HCPs] actually think they are helping you, but being honest with you; they create so much fear in you. Um [sign]... they tell you that you have to be responsible for your health, but on the other end, they are taking away your own... I mean you are most times not in charge of your health. They still dictate to you in some ways what you need to do. They tell you... this is what you should do; this is what you should eat. They don't have the time to explain things to you, they just give you medications, do tests, and sometimes they give you some flyers, that's all they do. (BALWD#4)

In contrast, HCPs expressed that provision of adequate information and knowledge alone did not seem to be the only response to managing diabetes effectively since lifestyle changes required largely depends on people's culture and beliefs

I think it is not just about providing information alone to the patient. Many cultures and beliefs castigate medical model of treatments. Many feel the information we give is not detailed or sensitive enough. (PRC3Nu)

From my understanding of African culture, information is never enough. Um... from the experience with people from the Black African communities, dietary pattern, beliefs and use of alternative remedies based on cultural values are quite complex... sometimes engaging but you will have to remain professional in your knowledge. Some of them might tell you the reason why they probably will not accept any of the advice and information, but others... you can tell from your discussion with them that it will be a great challenge for them adhering to your advice. (PRC1Dr)

On the other hand, one of the diabetes nurses stated that the high level of attendance and workloads at the clinic affects their relationship with patients. There is limited time to engage with people outside outlined services.

We, nurses, have higher workloads and many times, we have to multi-task to meet the demands of our work for the day. We do not have enough time to be discussing things in detail or getting information from the patient when we need to attend to another patient. (PRC2Nu)

Most of our patients come to the clinic just to either see the doctor or get medication. Moreover, when they are referred to us, many of them are not interested in listening to any health education talks because their mind is already made up. (PRC1Dt)

Although limited knowledge was identified as a significant issue for people living with T2D, individual responsibility to get adequate information was also reported as necessary.

We need education... education in our community. There is a distinctive lack of knowledge about diabetes and the risks. We need to get the right information for yourself and don't just rely on the magical pill you think the government can provide. You are not helping yourself by just relying on medication and doctors. People need to take up the responsibility for the condition. Manage the condition and don't let the situation manage you (BALWD#24)

One of the nurses interviewed, however, described how she has been able to provide more culturally sensitive information to the patient through seeking more information through working with colleagues in the Black minority ethnic (BME) communities

I don't think you can separate your profession totally from experience working with people in a cultural setting. I volunteer with a health organisation to work in Africa during the summer, so I go to Africa at least once in a year, and I've come to learn so much culture and values of people from the African communities. This helps me a lot in the way I provide information to people from such communities in the UK. You can relate to them... you could tell what they want and how they want you to present information to them, particularly when it comes to changing diets (PRC1Nu)

Participants with T2D explicitly addressed advice given by HCPs; advice received during and after diagnosis was felt to be good, but some of the participants felt they had to be satisfied with the information given by their HCPs providers, as there were no alternative remedies.

This further described how people put medical professionals in a powerful position and problem-solving role, perceiving them to have the answers to all questions about their health and wellbeing. Besides the conflicted view about the BsSAs' lack of adherence to advice and treatment regimens; the majority of the participants with T2D (BsSAs) only inclined to monitor their diabetes and perceive glucose level monitoring as important when experiencing symptoms rather than incorporating this as part of regular self-management behaviour. Participants had a limited understanding of the need for preventative care, suggesting that, despite great importance being placed on the guidance of HCPs, understanding or interpretation(s) of the information provided is limited.

5.5.7. Personal willingness and responsibilities

During the interviews, HCPs reported the need for personal willingness and motivation for behavioural change rather than people depending on professional roles and commitments to care. The HCPs emphasised the lack of individuals' responsibilities and how it plays a substantial role in self-management behaviours

... patients should have the willingness to want to change his or her unhealthy behaviours... you shouldn't rely completely on professional care. I might not understand your culture or I may have a different belief system, but then... if you know your lifestyle is affecting your health negatively, then you need to make the changes... I can't make the whole changes for you; I can only provide the necessary support and care available (PRC1Dr)

Yes, it is fundamental that the patient realised individual responsibilities. You can only provide them with what you have accessible to all (PRC2Dr)

Not everybody understands they have to be responsible for their health... yes, we are all (HCPs) trying to control the rate at which diabetes is increasing, especially among people from the Black African communities, but they feel everything should be done by the doctors. It's not only when they come down to the clinic or when they come down with problems. We have posters around... like in my son's school they've encouraged them to exercise more and eat more fruit a day. So, what they have done recently in their school was... 'Beat the street'. That's what they call the programme, so they've given them a card to encourage them to walk to school [sic], and they get points for that, so they have a machine at the school gate where they can top up their card, you just press it, and it comes up with movement light, white light to say go. So, every time they talk to each other, like, have you beat the street today? So it's like a slang now... have you had your five today... you need to beat the street [laughing]. They've encouraged kids to walk to school, and if you do that, you get back points and vouchers for books. These are what people should do; there should be a level of responsibility on the side of the patient (PRCINu)

It is important that people realise that doctors and nurses cannot do everything... the fact is we cannot solve the entire problem. If it's a cultural or a belief problem, there is much little you can do, don't you? (PRCINt)

One of the people with diabetes (BsSAs) acknowledged a similar view, demonstrating the importance of personal responsibilities in managing diabetes.

Yeah, I got a lot of inside information from friends... the internet and I read a lot. It wasn't like that 20-30 years ago, not everyone has access to the internet. Now everyone has access to the internet, and you could know as much as your GP. You know what I found out some time ago... the doctors are actually on the internet giving you your diagnosis or getting information about your medication. GPs are just human beings like yourself, and you can get information from the same source. You can inform yourself a lot from the internet. There are many more other things you can do to manage your diabetes on your own than just using medications to do it for us all the time. It's about encouraging people to try alternative remedies or method of controlling your diabetes instead of relying on tablets (BALWD#24)

On the other hand, some of the HCPs believed that PLWD are not sufficiently empowered to change unhealthy behaviours, resulting in their health getting worse and poorer. They reported that people still expect the NHS to sort out every care for them without taking personal responsibilities for their health.

... people come to their GPs with a programmed mind and certain thoughts about their diabetes....and they think their diabetes is the NHS's problem... the doctor's responsibilities to deal with, not theirs. People tell you, sometimes that they pay their tax and the government should be responsible for providing a good environment and resources to make their health better. They challenge you with all these... I pay my tax, don't I? (PRC3Nu)

No one wants to put in any extra work into being healthy anymore; they rely so much on the NHS to provide them everything since it's free (PRC4Dr)

Another theme that emerged during the interview with HCPs while discussing people willingness for behavioural change was the concepts of ‘patient-centred care’. According to the HCPs, it refers to the holistic and individualised care that promotes self-empowerment and embrace individual’s decisions, choices and preferences. HCPs emphasised that the holistic care covers the physical, emotional, social, or spiritual needs of the people. Although it involves dealing with the individual response to illness and the ability to self-manage their condition, the care provided remains centralised on medical knowledge. Therefore, other major factors outside medical understanding, which may affect self-management, might not be considered in the process of offering the care.

According to the findings from some of the BsSAs living with T2D, many keep their diabetes as a secret from their friends and families for a long time because of self-blaming and some not willing to lose out from certain family activities and events. To offer ‘patient-centred care’, the HCPs needed to see the importance of people’s opinion and look beyond their illness. This study finding suggests that people sometimes find it difficult to attend some of the diabetes sessions because of the idea of being seen as patients. Some of the HCPs acknowledged the importance of person-centred approach to care as it considers other social, cultural, psychological and economic needs of the person living with diabetes

Many don't like it when you refer to them as patients. The word patient often limits you [HCPs] from seeing beyond the person's illness or health status. I must say many of us are guilty of this when providing care to people living with diabetes (PRC2Dr)

The concept of 'patient-centred care' involves placing individuals at the centre of their care and working with them to strategize their own care. It involves independence and offering choices to the patient, but medically oriented. However, the way of thinking about people's illness goes beyond the current medical paradigm of illness and seeing people as a patient, to recognise at a deeper level how thoughts, emotions, experiences and beliefs affect our health. The process of getting well and putting people at the centre of their care, from this perspective, means looking at a whole range of both influencing and modifying factors in a person's life: their attitudes, beliefs, values, lifestyle, relationship with themselves and others, significant events and experiences that have meaning in an individual's life.

5.6. Perceptions of culturally sensitive interventions for self-management and implications for policy reformation (Policy and Decision makers)

5.6.1. Available networks for prevention and management of diabetes

Policy and decision makers (PLM and DCM) interviewed emphasised that diabetes treatment and care services were available at the hospitals and referrals, as HCPs could diagnose, treat diabetes and provide other necessary services. Prevention and treatment of diabetes remain a key focus among the BME communities, especially to prevent young people from obesity and overweight. Contrary to social issues, some of the underlying cultural issues were also highlighted through the interviews. One of the decision makers emphasised one of the crucial points about considering the underlying cultural issues in self-management behaviours. In her view, although some people demonstrated difficulties in diabetes management due to social issues, they were also faced with other cultural issues. A majority of the participants (PLM and DCM) recognised that there was limited involvement with the community as the diabetes model of care sits within the NHS mainstream.

I don't think that kind of stuff is happening in the community around prevention and management. I don't think there is enough out there on prevention and managing of diabetes. Sometimes it's quite a high profile in the news, but they're not much literature out there. If I was to go into many of the BME Communities, back to living in cities and talk to me about diabetes we probably wouldn't say it does affect them... you know, and I know that because I'm one of those people that continually goes... well it doesn't affect me (PLM2)

I think many people with diabetes, especially those with type 2 diabetes, seemed to talk expansively about their health issues in detail and more comfortable around their community setting to get support for their day-to-day challenges. So, it could be families, friends, religious centres, community groups and so on. I guess this is not the same experience when it comes to visiting your GP (DCMI)

The features of a diabetes model of care remain clinically led. HCPs education and support, some of whom are driven by the concealed power relations of biomedicine, dominating the processes of care. One of the PLMs acknowledged that the focus on the provision and integration of care within NHS services had been dominated by a discourse of biomedical control within the health system.

... I think we don't put much value on what the community can bring into the health system, which I think it's really important; it's like more of our priorities are in clinical care. The integrative care in place for diabetes in the UK should involve

more of the communities to provide a whole or a complete system of care for people living with diabetes (PLM3)

Participants (PLM and DCM) also broadly discussed the significance of community networks in diabetes prevention and management. Though the community is a major factor that is highly appreciated as a medium for disseminating health information to facilitate a healthy lifestyle, the appreciation remains silenced within the mainstream. One of the participants, however, spoke about the importance of the community network, for example, the church as a place that seemed to provide a sense of community in which people work together on common goals and inspire one another to lead better and healthier lives.

If you're part of a religious group and the group does health activities every day or regularly, you're more likely to go walking with the group and participate in those events, most importantly, because you share the same belief, values... you can socialise with them; you get to talk more about your health (DCM1)

Participants were asked to share their perspective on the possibility of picking certain healthy behaviours from community cultures to optimise peoples' health. They were very sensitive to the idea of picking certain behaviours embedded within community culture to improve healthcare. One of the participants described the benefits of this approach.

Everything that's out there... we are talking about people's culture, beliefs, values and knowledge, when it comes to healthy behaviours, though it might look hard and difficult we can implement some of them into our procedures for everyday diabetes management. It could be something new but refreshing for the HCPs, in terms of

building knowledge and empowering the patient to be more responsible for their health. As much as we try to provide the yardstick for people, we also need them to be able to use the right stick to walk (PLM2)

The dominant medical model of care reflected above shows lack of recognition of the broader social-cultural model of health as espoused by some of the policy and decision makers. The dominant discourse about diabetes care is defined by the usual narrow parameters of biomedicine and professionalisation of HCPs' expertise. The assertion of dominant professional power and knowledge continues to define the debate about integration of community knowledge.

5.6.2. Multiple challenges to culturally-sensitive diabetes intervention

Risk of saturation

The risk of general practice becoming saturated emerged as one of the main challenges to providing optimal cultural sensitivity to diabetes care. Some of the participants (PLM and DCM) informed that diabetes care services could become saturated as different communities have different cultures. However, it was noted that the health system needs to review some of the health policies by shifting from patient-centred care to person-centred care.

We always have been willing to take on more and more stuff to improve the health care provided to people living with diabetes, but we also need to be careful about getting our services saturated. The question is how many cultural kinds of stuff are we going to put on board. (PLM1)

... It is impossible for HCPs to know all the health-related beliefs of all these different cultures, but it is also important for them to be aware of cultural differences and value that patient display in their health behaviours (PLM3)

On the contrary, one of the PLM has a different opinion on the health system being driven by the HCPs' awareness of people's culture.

...they just don't have time; they cannot understand everybody's culture and belief. It is just not possible; there is no time for that service. The HCPs are doing their best by providing the available service. I have no complaints about the diabetes service at all. (PLM4)

Lack of integration between lay and expert 'medical' knowledge

The role of lay knowledge and its relationship to expert medical knowledge was largely discussed in terms of the essential support it could add to health promotion and improve health care services for PLWD. Some of the participants (PLM and DCM) emphasised that the disintegration of lay knowledge and expert knowledge in the mainstream health care system reduces the level of delivering optimal care. These participants felt people find it to be hard to participate in integrated care and specific diabetes sessions because of the power struggle between professional knowledge and lay knowledge.

Abating trust in medical expertise and more access to alternative health information sources, especially through media channels often alter clinical decision-making in providing health care (PLM1)

One of the DCM argued the need for better individual's responsibility for managing diabetes risks positioned within the diabetes policy as being active and getting to know health service consumers.

...this helps to contribute to the more patient-centred care and increases accountability for lay knowledge and clinical encounters with service users (DCM1)

On the other hand, two other participants (PLMs) acknowledged that the increase of evidence-based practice with the mainstream gives more rights to medical power and generalisable scientific knowledge over lay knowledge. One of the participants further gave emphasis on evidence-based practice resulting in the disease being treated objectively in isolation from the individual's experience of their everyday life.

...separating out and managing individual's lifestyle behaviours in isolation... just within the medical knowledge, prevents the assessment of how other factors interrelate... potentially leading to failure to deal with the 'real' issues that the individuals might be facing. As the mainstream health services move towards a long-term medical model for chronic disease and risks of complication, the meanings, beliefs and morals that people attach to their health behaviours and lifestyle become very much important when providing care. We are moving towards that direction gradually in other health issues like obesity, but we still very much slower when it comes to diabetes (PLM2)

The need for integrating lay knowledge with medical knowledge was seen as paramount in understanding the broader factors that impact on health behaviours.

Exploring how lay knowledge can provide a more refined understanding of other factors contributing to self-managing behaviours is very important. The care model needs to incorporate the subjective lived experience of individual's into understandings of health behaviours (PLM3)

Participants (PLM and DCM) expressed the boundaries of medical responsibility and lay contribution to knowledge but also highlighted the need for incorporating certain knowledge. This was seen to contribute to the understanding of lay concepts of disease causation by highlighting the opinions that people hold about the causes of their illness.

Given the difference between lay and expert stance about illness, awareness of lay beliefs around disease causation may allow for better tailoring of health promotion strategies. It may also provide insight into the behaviours adopted to avoid or manage illness (DCM2)

Despite the urgings for integrating lay knowledge in mainstream services, some of the participants criticise the extent and reliability of this knowledge.

The information provided on personal experience of illness can be incomplete and bias. Although the information might look valuable, the understanding only reflects the experiences of one person. The question will then be; can these be used to generalised care for others? There are less technical skills from lay knowledge to diagnose or predict an illness (PLM1)

According to some of the participants, the main barriers to integrating lay knowledge with medical knowledge increases the uncertainty and challenges to sensitive cultural programmes for diabetes management.

Compliance model of care

The compliance model underpins therapeutic prescriptive approach to care and evaluates the outcomes of people managing their diabetes by their ability to adhere to prescribed therapeutic regimens. Participants describe that this traditional compliance model does not allow shared responsibilities, or the independent thinking needed in self-managing diabetes.

People rely on HCPs to make decisions and give instructions on what to do and how to do it while they try to comply with the guidelines. This model care does not allow cultural choices fully (PLM3)

Some of the participants propose a new model that allows a better partnership between HCPs and persons with diabetes to improve empowerment and for better disease outcomes. Participants emphasised that the partnering relationship allows HCPs to provide better self-management support, which goes beyond providing information and includes helping individuals develop problem-solving skills, improve self-efficacy, and support the application of cultural knowledge in real-life situations

Self-managing diabetes requires emotional and behavioural skills to handle the complex self-management tasks involved in recommending treatments. If the given structured guidelines are not culturally sensitive enough to allow people's

engagement, then they will struggle with the task. And this doesn't enable HCPs to be culturally skilled (PLM4)

Although the participant identified the multiple challenges to culturally sensitive intervention and demands, they also observe the importance of knowledge building among PLWD and HCPs as ways to provide self-management support.

5.6.3. Strengthening diabetes self-management as a means of improving health outcomes: Collaborative practice

All PLM and DCM interviewed stated government's responsibilities in making changes that will enable healthy diet and lifestyle changes among high-risk communities. Some of the government interventions identified were food labelling, health awareness, health education, self-management programmes empowerment and community participation programmes. Diabetes education and self-management programmes were seen as essential for providing optimal care for diabetes and other chronic disorders. However, the cultural sensitivities of the programmes remain discreet. Participants described a thin cultural knowledge in self-management programmes and health promotion due to a range of diabetes clinical outcome measures.

Participants (PLM) also mentioned several changes in practices and local policies to support local communities in diabetes care and management. However, many of these changes are being coordinated at the national level.

The big thing you might know recently about health is the sustainability and transformation plan for self-management, you may have heard about this, the idea

that more services will happen in the local community rather than actually within hospitals. The idea is to cut out some of those hospital beds so that there will be more services in the community. I've been involved in making sure that the voluntary and community sectors and in particular our workforce are recognised as a workforce that can help to deliver the strategies for improving care at the local level (PLM2)

When this participant was further asked about when the prevention and management of diabetes remain significant on local policies, she stated;

Diabetes agenda comes up every time because it's a long-term condition. It's integral through the entire sustainable transformation plan that talks about self-care, prevention, and independence... all of that is about those long-term conditions which diabetes is one of them. Obesity is a big issue, but obesity is part of diabetes. So I can see the links, whether other people see the connections is another issue, whether the general public knows the connection between that, maybe not as much as well as they should do that about education, that's about people being educated about diabetes. Though we have not specifically said about diabetes here, it is the long-term condition, and so that's part of it. Moreover, the work that I am doing around bringing together voluntary organisations to work around the sustainability and transformation plan certainly focus on diabetes. It is going to focus on the five main things to public health now, so obesity is one of them, within the long-term condition, its cancer, its diabetes. It's all of those things really; it's smoking, lack of activity, all of the things that would affect somebody's life if they have diabetes. So though it's not explicit, it's giving the fact that it's in there (PLM2)

When I asked some of the participants for the rationale for changes to policy and practice, they were often vague but provided some reasons for the changes. This idea of coping with chronic disease management and thus re-evaluating individual care priorities was usually what promote diabetes care model. The care model was adopted as a GP led practice for self-management support.

It is interesting to see how the NHS is tackling the challenges of diabetes care as a chronic long-term condition, but the debate remains on the issue of expertise and the level of integration of care. This develops itself on a debate as to where exactly a health professional contributes to the care process (PLM4)

...local experience of people that uses the service should form the bedrock of any diabetes care redesign if we are talking about a collaborative practice (DCM1)

The structured, holistic approach was recognised as a key lead to better care and reduced health costs.

...the focus should be clearly on different networks and organisations working together, not functioning as unequal bodies of knowledge. This is not to be interpreted as, which should be the dominant force in any area of expertise but to help facilitate integrative care. Then, we need to start with a collaboration with community networks to improve health outcomes among high-risk communities (DCM2)

Although there were emphases on the importance of self-managing diabetes as a way to improve quality of health, one of the participants argued that the ideology of free healthcare

service devalues the idea that people should function independently when managing their health.

People often assume it is all free service of care, but it is not a free service. There should be an individual responsibility to care (PLM1)

On the other, some of the participants identified the need for people to have the right skills that would promote self-management behaviours

The focus is for people to engage with recommended treatment, but it is also about having the right ability to self-manage. Individuals should be able to participate in the management process without much intervention from HCPs. These things should be considered for reducing cost (PLM3)

Underlying this view that people are responsible for their health contradict the idea of collective prevention of disease. Although self-management emphasise one's own responsibility to care, some of the participants noted that HCPs commonly use the word and self-management should not only be about dealing with an illness but health promotion and prevention of diseases.

The challenge is to know who needs the support and who will be able to self-manage. You cannot know this if you don't go into these communities. We need more health awareness in the communities, not all about structured health education. If they are not rightly aware, they cannot participate (PLM2)

It is equally important to self-manage patients by providing the right support to them and that they can make their own choices and not just the choices of the healthcare provider (DCM1)

Although self-management was linked to the rhetorical strategies of saving cost and promoting better health outcomes, some of the participants, however, did not consider the self-management approach as a way to save money on the NHS.

The fact is, this is not a less intense way of treatment cheaper than traditional healthcare. We need to go back to the traditional way of health care if we want to cut costs... have a more collaborative practice (PLM3)

Community-based intervention was reported as a key focus in strengthening diabetes self-management and promoting health

... If we can get those key messages down to the communities, these communities will start to talk about those issues themselves, and that's where the real change happens. They feel more empowered to speak of those things, and how they the health of the older generation but also preventative for those people that don't have diabetes, you know... and then also installing the education with our young generations as well because it's all about early intervention and Nottingham is an early Intervention City. That's what we say we are and if we're talking about early intervention, that has to happen at every level, not just education you know it's across the board (PLM2)

And I think it is very important that the general practices, health professional's community networks work together and communicate together. And I sincerely think that we need another program for that (DCM2)

...communities are very important, which is where we are now spending a lot of time, is to organise care programmes that can effectively engage diverse communities properly. (PLM1)

When participants were asked further about evidence on the impact of changes in practice at the local level because of emerging trends in practice and policy, many of the participants did not have a clear view on the impact of these changes. One of the participants, however, reported that though there is no evidence for a reduction in the cost of health care, there is evidence of increased health outcomes. Not everyone can directly self-manage their diabetes, therefore, would still require supports and skills from HCPs

... yeah, they [HCPs] have to work alongside with many patients on all the factors that could contribute to their health outcomes and not only give information but provide adequate support and care to the patient. That is why it is important to see things from a broader perspective when redesigning care and it should be a continuing process and intervention (DCM2)

5.6.4. Use of alternative services for diabetes management

The use of alternative remedies in the treatment and management of diabetes was also discussed largely during the interviews with the PLMs and DCMs. Some implications were identified for both individuals living with diabetes and the community.

5.6.4.1. Implication for people living with diabetes (PLWD)

As already identified in section 5.4, the majority of the BsSA living with T2D often resorted to the use of alternative remedies either as the sole treatment or as complementary remedies to recommended and prescribed medications. The majority of the participants (BsSA living with T2D) interviewed use alternative remedies based on cultural values, efficacy, fear and mistrust of medical treatments, and religious knowledge. This mainly modifies individual's overall care and management of diabetes. The policy and decision makers also noted the implications of the use of alternative remedies on the management of T2D.

You see... when things don't work for you or you, don't believe in specific treatments to work, especially when you've been on the sickness for the year with no improvement [sic]... you tend to try out other things that could work. I can relate to people trying out other remedies. Diabetes is a long-term sickness and demands a lot to manage the health condition. Now, I am going to give you an example. I've been battling with arthritis for years, and I was placed on some medication... some did work for me, but some didn't. So, I tried out acupuncture, and it's really been effective in managing my pains. I only use it though to complement my medication occasionally. But it reduces the time I spend with the GP and how often I use my medication... in a way reducing the cost of care to the NHS. I can relate to the use of alternative medicine, but there are many debates on whether these remedies can be integrated into conventional medicine (PLM3)

Another participant (DCM) acknowledged the use of alternative remedies by many people was the search for improved care and cure of disease. However, he identified the issue of

evidence-based information on its efficacy and that some alternative remedies might not be considered within the NHS because of negative outcomes and limited supporting evidence.

... It is about providing the evidence of what works with the use of alternative remedies. The promotion of this evidence can then be used to allow the use of alternative medicine. But this can only be done by widening the knowledge of what works in alternative remedies and assess what is lacking from conventional medical care (DCMI)

Participants were further asked whether there was an ideological debate between conventional medicine and alternative medicine and the implication of the diabetes care model. One of the participants felt it had become more of a political debate on the traditional knowledge underpinning the practice of conventional medicine. However, he further demonstrated the risk of alternative medicine within the mainstream system in the UK.

... the use of alternative remedies without conventional therapy poses a major public health concern in the UK (PLM1)

On the other hand, one of the participants acknowledged that the use of alternative remedies had been promoted lately with the increased use of the media and global recognition of Ayurvedic medicine.

There are loads of information online; through the media about the cure of diabetes... and what works for diabetes, whereas your GP will never give the information about the cure for diabetes, it's all about treatment and management. The information from

the media is enough to convince those that do not trust medical treatment to give in to the use of alternative remedies (PLM4)

5.6.4.2. Implication for community-based services

While acknowledging the effective role of biomedical care facilities in the care and management of diabetes, participants [PLM and DCM] reported that use of alternative care services particularly those practised within communities was equally attractive for several reasons. One of the participants described this in-depth.

There was a political programme where one of the MP's was talking about term hospital cuts and people needing to go back to what we used to do in what was considered to be the old days... when people would manage their health better; people would use alternative remedies; they would use homeopathic remedies, they would use all of these different things... you know. They use things that they used when they were if...if they're not from the UK that means back home, those kinds of things to manage their health. It will be on the agenda before you know it. I think what would then happen in the UK is there's got to be a fundamental shift in people thinking that the NHS can be everything for them because it's not... and it can't be, and it's not sustainable, and so we can't have the system totally broken. So, we've got to think about alternative ways for people to think about their health. But with that, you can't have people take what they think are alternative medicines or remedies that are not proven. That may cause an, even more, damage... you know what I mean... they may end up in A&E. So obviously increasing the health cost again. If we could come up with the public health message through community channels, that said these are some of the ways of reducing diabetes if you're managing your diabetes these are

*some of the alternative remedies that could work for you... do you know what I mean?
List of things that we may be recommended. Some of the herbal or homoeopathic stuff
is regulated. It has to be brought into the picture of community-based intervention; we
need to talk about it at local level up to the national level (PLM2)*

Participants reported that the use of alternative medicine is absent from the national agenda for diabetes self-management. There are no specific policies targeted at the use of alternative remedies in the treatment and management of diabetes. Alternative medicine is not an explicit idea of the government health policies, but one informant thinks that it is emerging as community intervention measures with increased advertisement through the media. Community knowledge on the use of alternative medicine might enhance the social support system available for diabetes care at a local level. Some of the participants explicitly presented this as an interpretation of integrative care that could improve healthcare outcomes, but recently there is not much interest in this topic. A focus on self-management might increase the existing gap between the use of alternative medicine and conventional medicine.

*It is likely that community groups that we think need less care might be best capable
of promoting self-management at large (DCM2).*

*... the government need to improve research on the efficacy of many of these
alternative remedies. This could improve the provision of more person-centred care
and promote community health intervention at the local level (PLM3)*

5.6.5. Diabetes care transformation initiatives through community networks: Integrative care

In terms of providing support that could allow more engaging and integrative care, the PLM and DCM identified various initiatives that could create a culturally sensitive system for the management of diabetes among various groups. The majority of the PLMs and DCMs seemed to find informal community networks supportive, but few of them were concerned about the challenge it could bring to professional knowledge in terms of integrating lay perspectives into professional practice.

... I think making HCPs think beyond their medical roles, and beyond their currently structured diabetes, care model can be a challenge. Taking care outside the mainstream could be a long walk (PLM4)

One of the major suggested initiatives was to broaden the continuity of care beyond the hospital setting and through community networks. Some of the PLM and DCM recognised that implementing such strategy with HCPs could improve individual's access to care and understand better the cultural needs of people with diabetes through their community networks. They reported that this could further provide a platform for HCPs to share information with key 'gatekeepers' to help promote positive self-management behaviours among community members.

Promoting care through community networks could influence positive personal, social and cultural beliefs and help to improve self-management beliefs. The gatekeepers of these communities are key people that can also help in creating awareness and providing support to people living with diabetes among their communities (PLM2)

Another participant identified that integrative care could also help to improve HCPs' performance in terms of cultural awareness and to reduce fragmentation of diabetes care

The patient could get to communicate with HCPs better and vice versa. They both could become more aware and informed about certain cultural lifestyle could impact on health behaviours and outcomes (DCM2)

One of the important suggestions of the policymakers that could promote integrative care was to provide HCPs with adequate cultural skills. Some of the PLM and DCM recognise that this could help in providing efficient support facilities through various community networks.

I think it is important to provide suitable training and individual development of cultural programmes for health professionals to improve their efficiency in providing better care for people living with diabetes, especially for those from culturally rooted ethnicity. It also allows people to engage more with the service (PLM3)

When we create an environment that appreciates the culture and sees it beyond being a barrier, it creates better chances for efficient care... professionals can then easily know which care should be offered. They [HCPs] need the right skills... cultural knowledge and information to be able to deliver efficient self-management programme (DCM1)

The increased role of community networks alongside HCPs creates the need for more cooperation to deliver the necessary care for people living with T2D. Participants emphasised the importance of collaborative care that would increase cooperation and sharing of knowledge among GPs, local authorities and community services. Local authorities and

community networks become more important in the accessing and distribution of resources and information that could promote specific diabetes care activities within the community. HCPs could be more aware of community activities that could promote health care behaviours and increase the capacity of negotiating relationships with people with diabetes. Self-management support requires awareness of cultural identity and the ability to deal with individual network relationships within a community setting.

5.7. Summary

In summary, this chapter presented a thematic analysis of 28 BsSAs living with T2D, 10 HCPs and 6 policymakers interviewed. This chapter has focused on the lived experience of people living with T2D, examining how practitioners experience and negotiate healthcare practice with the BsSA communities and assessing the perceptions of policy and decision makers on the cultural sensitivities of self-management intervention among high-risk communities.

These findings reveal basic emerging data and important cultural factors and beliefs that affect diabetes self-management behaviour among Black African communities and add new knowledge about professionalism in healthcare and other sociocultural barriers to accessing health care. The finding explains the association of themes that emerged during the analysis of initial interviews conducted with Black Africans with T2D. Analysis of these findings highlights how the factors and emerging themes interrelate and interact with one another, and provide further insight into answering the research questions for the study.

The respondents show the importance of more knowledge about the role of culture and health beliefs on diabetes self-management behaviours. HCPs described self-management as an

individual-centred and their practices as holistic and empowering which they see as a right approach to health care services that build the confidence and relationship with HCPs. Although there were criticisms about the traditional medical approach given to health by conventional medicine, none of the HCPs interviewed suggested that alternative remedies should substitute biomedical regimens. Instead, they (HCPs) and many of the PLMs and DCMs emphasised on the significance and benefits of a culturally-centred intervention that could improve healthcare services; delivering community engagement programmes and creating awareness on community networks. Nonetheless, they highlighted possible barriers of individual and lay belief beliefs with the biomedical model. Furthermore, there were suggestions from the respondents (PLMs and DCMs) for the need for a new model of channelling sensitive cultural intervention through the community networks.

Completed analysis of primary data with other secondary data will be further discussed in detail in chapter 6 of the thesis.

CHAPTER 6

DISCUSSION OF FINDINGS

6.1. Introduction

This chapter discusses the research findings presented in chapter 5, starting with a detailed discussion of the outcomes of the study. This is followed by the discussion of the identified principal findings on cultural factors and their significance on diabetes self-management behaviours among Black Africans living with T2D. It ends with a discussion on the perspectives of the HCPs and policymakers' and their responses to culturally sensitive intervention to improve health outcomes among the BsSA communities.

The latter part of this chapter will take a closer look at the implications of the study on diabetes policy, community mobilisation for improved health practice and the contribution of research. It then concludes with a brief discussion of the strength and limitations of this study.

6.2. Summary of research findings

The study findings have been presented in Chapter 5 and organised under specific themes addressing the research questions and objectives of the study (see figure 5.1). This study uses the concepts of sociocultural model and PEN-3 public health cultural model, which moves beyond an individualistic approach used in addressing health behaviours (see 2.7.3 and 3.6.2) and the analysis of narrative data to understanding the lived experiences of BsSAs diagnosed with T2D. The sociocultural approach to health management proposes that people's access to treatment, choice of healthcare and self-management behaviours should be viewed through the prism of cultural knowledge and individual experience within the context of a community

setting. Proponents of the sociocultural model argued culture and belief system should be incorporated explicitly into understanding health disparities, illness and choice of treatment as a multi-factorial pathway that determines people's health outcomes (Foster, 2009; Sanderson, 2010). On the other hand, the PEN-3 public health cultural model focuses more on collective health behaviours of a community setting and how this forms building block that creates health beliefs outside of an individual's control and determines the decisions that individuals make about their health and the choice of treatments (Airhihenbuwa, 2007; Iwelunmore et al., 2014).

The anthropological perspective of health knowledge and narratives helps in understanding the cultural nature of T2D self-management and its inhibitors (Greenhalgh et al., 2015). The sociocultural model as a behavioural framework holds that an individual's experience of health in social and cultural contexts should be explored and incorporated into the ecological and cultural aspects of disease and health outcomes (Uskul, 2010). In this study, ethnographic principles were used to examine the experience, voice and needs of PLWD. This study's most significant contribution is showing how culture plays a significant role in self-management of diabetes through multiple health and healing channels including cultural knowledge and perceptions of diabetes; individuals' experience of self-management; health-seeking practices; modification of diets; family values superseding individual needs, and engagement with HCPs. In addition to examining the significance to policy and health practice reform, this study's other contribution is showing the importance of recognising silent voices and narratives from these communities (see comprehensive discussion in 6.3.4). The community can become involved in the policy process and be empowered and given their voices (be unsilenced as it were) through ways that do not need to be controlled or managed by the professional practitioners. It also recognises how the use of community networks could

improve access to health care and reduce the negative impact of culture on health outcomes (see comprehensive discussion in 6.3.5).

Study participants' narratives demonstrated the need to consider sociocultural issues and self-management needs. When people feel embedded in sociocultural expectations, for example, values of cultural identity and family connectedness, their diabetes self-management may take a lower priority over efforts to solve other more immediate problems. As part of this study, BsSA people with T2D suggested the development of culturally sensitive health activities through community networks. However, HCPs emphasised that they required more cultural knowledge and skills that could facilitate addressing other social issues, for example, gender roles, lack of social connectedness and attitudes towards mainstream culture, which are factors contributing to health disparities identified within the communities.

6.3. Discussion of the study principal emerging findings

6.3.1. Cultural knowledge and perceptions about T2D and self-management among BsSA communities (Theme 5.2 and 5.3)

This study found that cultural knowledge of BsSAs living with T2D includes social and family experience; family diagnoses; medical knowledge about the disease; and other individual experiences that have a collective impact on health and management of the disease. The cultural beliefs and knowledge of diabetes amongst these communities reflect the dynamic cultural relationship between health and traits of African beliefs. Cultural beliefs are rational, but ethnographers understand they are acted upon by individuals' experiences, even though individuals' decisions on health may be constrained by other external structures.

Diabetes knowledge

The study participants based their responses and views about T2D diagnosis and self-management on their individual, family and societal experiences with the disease in their country of origin and the UK. These findings support the findings from other studies demonstrating the impact of individual experience on the interpretation of illness and management (Cameron and Moss-Morris, 2010; Abubakari et al., 2013, Nettleton, 2013). Study participants occasionally referred to medical information about T2D, often provided by HCPs, such as pancreas malfunction and lack of insulin production as the cause of T2D. However, there were traces of scepticism in these responses as many the BsSAs with T2D seemed fatalistic about the onset and prognosis of T2D when asked about disease prevention and treatment. The findings suggest limited diabetes awareness and knowledge levels among the study participants as only a few understood T2D before diagnosis. These findings support other studies on the uptake of primary and community diabetes and long-term respiratory conditions services among Black Asian and Minority Ethnic (BAME) communities in Nottingham City (Bashir et al., 2016). Many of the study participants were not sure if diabetes was preventable, treatable or curable. Although a few of the participants had the conviction that diabetes can be prevented and treated with no further cases of illness or complications, knowledge about management was improved after diagnosis. Many of the study participants were still unsure about the causes of T2D as many other things, including existing health problems could be attributed to the diagnosis. Some of the things identified were: starchy, fatty and sugary diets; food preservatives and processed food; the stress of work; distress of migration; lack of natural and physical exercise; pre-existing diseases; medication side effects and other lifestyle factors such as excessive drinking and smoking.

Some of the participants who had a strong belief that T2D was hereditary and age-related also expressed scepticism that T2D's onset could be prevented by regular exercise or modification of diet due to cultural and environmental transitions. These findings support findings from other studies among South Asians, African Caribbean and other studies in Africa, demonstrating other ways of preventing diabetes or diabetes-related complications (Brown et al., 2007; Nam et al., 2011; Johnson et al., 2011; Lucas et al., 2013; Tillin et al., 2013; Patel et al., 2015). Similarly, studies with South Asians, Afro-Caribbean and other studies in Africa demonstrated that lack of awareness and ignorance (Schoenberg et al., 2009; Ashtarian et al., 2012; Swelieh et al., 2014; Harrison, 2014), misinformation about diet and treatment (Brown et al., 2007; Agyemang et al., 2009; Carr, 2012; Everson-Hock et al., 2013; Weightman et al., 2013), lifestyle (Oldroyd et al., 2005; Tillin et al., 2013), cultural transition (Higgins and Dale, 2009) and lack of community engagement with health intervention programmes (Netto et al., 2007; Noakes, 2010; Johnson et al., 2011) as a major risk factors for poor outcomes of diabetes management. Study findings also showed that people's narratives confirmed how late diagnosis hinder people from managing their diabetes effectively and increases the risk of complications. Nonetheless, the lack of culturally sensitive government action and policy guidelines on the prevention and management of T2D at the community level was reported as contributing factors to the prevalence of diabetes among the Black African communities. These findings contrast with Schoenberg et al. (2009) argument that the knowledge gap in illness perception undermines HCPs' ability to appropriately address T2D management and disease prevention at an optimal level.

Another significant finding in the study relates to a misconception about early diagnosis and fear of the unknown, as described by some of the participants. They described living with T2D, and how early diagnosis increased their anxiety and concerns about diabetes and the

risk of complications. It did not necessarily affect the way they manage their diabetes. Many become too anxious about making sure they do the ‘right’ thing. There were phrases used by some of the participants to describe this; “...*unfortunately, I am one of those that unfortunately will have to live with it*” (see 5.3.3, *BALWD#8*), “*you do not die of what you don’t know*” (see 5.3.3., *BALWD#23*). Study participants talked about their frustration with coping with the disease’s symptoms and prognosis, for example, the exhaustion, which made it difficult for them to participate in other social and family activities. They also discussed their fears about the disease, how their health deteriorates, which led to the erratic use of medication. It was particularly distressing for study participants whose vision and the nervous system became severely weakened because of neuropathy and retinopathy. This finding supports other studies that demonstrate that fear and anxiety about diabetes-related complications and early diagnosis impact on their well-being and results in poor self-management (Funnell, 2006; Mosnier-Pudar et al., 2010; APPGD, 2015). The study findings also support Carr’s (2012) argument about insufficient knowledge about diabetes management and how these negatively affect people’s ability to adopt healthier lifestyles or modification diets even after diagnosis. Limited knowledge about diabetes amongst the study participants was also associated with low perceptions about the risks of diabetes, which could further result in late diagnosis and treatment. Thus, signs and symptoms of diabetes were key triggers for the choice of the participants to seek care.

Study participants were very familiar with the biomedical treatment and guidelines for diabetes management. Nonetheless, shared cultural knowledge of treatment not directly related to the biomedical model was readily identified in the case of study participants who agreed that a person could still manage diabetes effectively through other alternative remedies and not wholly rely on medical treatment. The majority of these study participants

could clearly recall home remedies as a major source of treatment for many diseases like diabetes. Since many of these alternative remedies were found to be less accessible in the UK, many do rely on medications to manage their diabetes. They talked about their cultural beliefs of T2D prevention as beliefs that they had generally accepted from families and friends, which shows the collective mentality and knowledge acquired mostly from their country of origin. Study participants have developed a cultural belief model about T2D prevention that integrates both the cultural knowledge and biomedical model from their country of origin as well as Black African communities within the UK. There was no difference in this integrated knowledge and beliefs as many of the perceptions are culturally embedded. The finding that study participants gained their cultural knowledge from friends and family support other findings conducted with South Asian and Afro-Caribbean people living with T2D in the U.K, which established that cultural beliefs about T2D beliefs were particularly influenced by families and friends as well as childhood memories of living in the country of origin (Lawton et al., 2006; Brown et al., 2007; Johnson et al., 2011; Patel et al., 2015). This collective family memory combined with individual and family experiences with T2D contributes to their health-seeking behaviours. The findings also showed that individual factors (age, belief, attitude, and health practice), interpersonal factors (family, friends and other social networks) and other social factors play an important role in influencing people's decision to seek care and what type to care to seek. These findings supported the argument of Fisher et al. (2005) suggesting the need to consider the individual's perspective and cultural practices when delivering diabetes self-management education.

Social stigma and discrimination

This study also shows that limited awareness about diabetes and misconceptions among the BsSA communities as a major factor for social and cultural stigma, social expectation and the

feeling of discrimination among the communities. However, some of the study participants acknowledged the occurrence of indirect or direct stigma and discrimination, particularly before and after diagnosis with T2D. This is more so in cases of observable signs and symptoms such as abrupt weight loss like some other diseases such as HIV/AIDS, tuberculosis and cancer, and consequent withdrawal of participation in family events. Some of the participants express the fear of disclosing their illness due to the cultural stigma attached to unhealthy behaviours, and eating patterns, particularly among people from African and Asian origin. It is apparent through the interviews with people from the BsSA communities that T2D stigma did not only impact on the individual affected by the illness but also impacted the family connectedness. This supports the argument of Potter et al. (2015) and Winkley et al. (2015) about the importance of identifying diabetes as a stigma-related illness, but it is often not recognised as such by HCPs. Increased cases of stigma may reflect a lack of awareness through community channels and the fact that health information is mainly disseminated through clinics and HCPs. Other studies have also linked misconceptions, lack of awareness and local health beliefs about T2D to social stigma and discrimination (Noakes, 2010; Brown et al., 2007; Mosnier-Pudar et al., 2010; Browne et al., 2013; Harrison, 2014). The study participants felt that a good awareness of diabetes and its related complications through community channels could contribute to better management, reduce the fear of stigma and improved health behaviours among the studied communities. This reflects broader moves and shifts towards re-contextualising diabetes as a health issue beyond medical representation. This would undoubtedly create broader knowledge of other sociodeterminants of health and initiatives for health promotion among communities that are directly or indirectly affected by diabetes stigma.

Food choices and diet preference

Another significant finding from the study relates to the modification of diet among the BsSA communities in the prevention and management of T2D. When discussing T2D in the Black African context, it is important to recognise the role of traditional food and diet patterns. Although some of the study participants believed that solely African diets were not particularly a good way to manage T2D due to the high composition of sugar, fat and starch in the diet and included large portion sizes, many of the participants argued that African food has curative and medicinal properties that could support their health. Study participants also reported that traditional African food serves a significant cultural role in their lifestyles, especially at social and family events, such as ceremonies, weddings and festive activities, where families and friends share cultural food from the same plate. This is a key tradition that shows family cohesion and provides opportunities for building relationships. Therefore, many of the study participants sought to alter their diets by reducing serving sizes of African foods, eating in moderation and making traditional dishes with less fat and oils. They believed that this process would allow them to manage their diabetes effectively. Many of the study participants reported consuming western processed foods increased the risk of their health deteriorating and other diabetes-related complications. However, the study participants with T2D acknowledged that modifying their traditional diets could be challenging when following through HCPs diet regimen because African foods are generally seen as unhealthy. This finding of study participants struggling to modify their African diet, have also been reported in other qualitative studies conducted among Afro-Caribbeans and South Asians within and outside the UK (Scott, 1998; Brown et al., 2007, Lawton et al., 2008; Bramble et al., 2009; Johnson et al., 2011). Study participants with T2D believed that the struggle was as a result of the lack of cultural information about African diets included in diet regimens from HCPs. These findings support the arguments of Grace et al. (2008), Wood et al. (2010) and

Everson-Hock et al. (2013) on limited dietary advice from HCPs and focus on western diet regimens for diabetes management. Consequently, study participants' cultural beliefs about the benefits of modifying traditional African diets proposed the recommendation of an inclusive dietary guideline that includes both nutritional values of African diets and suggestion of substitutes that could still offer culturally appropriate diets for managing T2D. There appeared to be gaps in identifying the cultural needs and adjusting to meet specific dietary needs. These could enhance self-management behaviours among BsSA communities, increase their personal satisfaction with the diabetes service provision and, eventually, improve their health-related outcomes. Thus, people with T2D would benefit from diabetes intervention and regimens that include nutritional advice for modifying their traditional African diets. It is also important that HCPs consider the wider sociocultural factors related to nutrition that could act as facilitators for PLWD to participate effectively in other lifestyle intervention programmes.

6.3.2. Efficacy of alternative remedies and medical syncretism (Theme 5.4)

The most significant cultural beliefs that study participants shared about how to manage T2D effectively were the cultural values and efficaciousness of traditional/alternative remedies, the importance of spirituality and religious beliefs and concepts of healing. The tensions between study participants' cultural beliefs about T2D and translating their cultural beliefs into health-seeking practices and behaviours were apparent when they self-managed the disease daily. Individuals and family members using existing traditional healing practices for diabetes subject the conduct to care and management, to a lay diagnosis of the signs and symptoms. Based on the diagnosis, decisions to seek care are then made on the nature of the care and treatment to be sought. As observed in the current study, decisions to use unconventional treatment mainly reflect the influence of friends and family members who

may have been diagnosed with T2D and attest to the use of alternative and/or traditional medicine. Therefore, the use of alternative remedies becomes the first-call treatment among the BsSAs living with T2D before eventually turning to the biomedical treatment if symptoms persist. The reverse is the case of turning to prescribed medications if biomedical treatment seems not to be effective for individuals' needs.

Efficacy of alternative remedies

The use of alternative and/or traditional medicines play an important role in an individual's decision to take and adhere to 'western' medications. Many of the study participants with T2D believed that using traditional or alternative remedies helps to effectively control their blood sugar levels and reduces the use of other medical treatments as well as improving their overall well-being. While some of the study participants with T2D use traditional/alternative remedies sporadically due to their cost and efficacy, others use it regularly with the intention of stopping the use of prescribed medication over time. Similar studies have shown that people living with T2D delay medical treatments, even after identifying symptoms, hoping that alternative and/or traditional remedies will alleviate their symptoms (Rutebemberwa et al., 2016). However, few of these study participants with T2D who either were retired medical personnel or seemed to have good knowledge of medical practice did not believe that traditional/alternative remedies were an effective treatment for T2D because of the lack of evidence to support its effectiveness.

Beliefs about T2D and the efficacy of alternative and/or traditional medicine are similar to those identified in studies among British South Asian and African Caribbean with T2D in the UK (Scott 1998; Moss and McDowell, 2005; Brown et al., 2007; Patel et al., 2015 and Lucas et al., 2013) and outside the UK (Egede et al., 2002; Aikins, 2005; Awah et al., 2008; Ogbera

et al., 2010; Many et al., 2012; Keter and Mutiso, 2012; Semanya et al., 2012; Chinenye and Ogbera, 2013). Most of these previous studies found that African traditional medicines and remedies were used concurrently and interchangeably with prescribed medication as an effective complementary treatment for T2D and overall well-being. The use of bitter plants as a natural treatment '*...it is all from a natural source*' (see 5.4.1., BALWD#1) to treat the sweetness in the blood '*When you have too much sweet in your body [laughing], you need something bitter to wash it off, don't you?*'(see 5.4.1., BALWD#2) suggests an attempt to balance the function of the body to control glucose levels. The African medicinal plants that study participants used to treat T2D included, green tea, Aloe Vera, bitter leaf, bitter kola, celery, okra, cinnamon, ginger, garlic, cucumber and pumpkin leaf (Ugu).

Concerns about the toxicity of prescribed medication (often for multiple illnesses) and the biomedical representation of diabetes treatments were identified as contributing factors towards self-management behaviours and lack of adherence to their medical treatments. In this study, many the participants with T2D held the belief that natural remedies are more effective than prescribed medications (often for multiple illnesses) that have gone through stages of processing, which sometimes reduces the natural compositions of the medication or increases its toxicity. The study participants' cultural belief that traditional or alternative remedies were efficaciousness originated primarily from direct and indirect conversations with family members and friends that have personal experience with the use of traditional medicines in the treatment of T2D or memories about the treatment of the disease from their countries of origin. This study also identifies the indisputable role of medical pluralism in diabetes self-management among participants from the BsSA communities where herbal remedies and traditional foods are mostly used alongside medical treatments, although there were few of the study participants that use traditional remedies solely as the only form of

treatment for diabetes. Cultural beliefs about traditional remedies as natural treatments play an important role in an individual's decision to take western medicines or the use of western medicine as complementary medicine (Moss and McDowell, 2005; Nichter, 2008). This evidence is consistent with the findings from Semanya et al. (2012), Chinenye and Ogbera (2013) and Harrison (2014) who confirm that people use traditional remedies in the treatment of diabetes because they trust them, and it ties into their cultural beliefs and traditional practices and reflects the values and significance to improved health through natural and non-toxic means.

However, five of the study participants expressed fear about the use of traditional medical causing more harm to their health and would prefer them recommended by their doctor. Although there have been few studies on the efficacy of some traditional remedies such as Aloe Vera (Arora et al., 2009) on controlling glucose and lipid levels in people diagnosed with T2D, few of the study participants were concerned about the limited evidence to support the efficacy of most traditional medicines. Some of the HCPs interviewed also showed concern about the lack of evidence to support the efficacy of most of the alternative or traditional remedies. Yet many of the study participants with T2D strongly believed that the use of traditional/alternative remedies along with using the biomedical the model would help them to treat T2D and control their glucose more effectively levels. They believed that policymakers and HCPs should conduct further research on the use of alternative remedies in the treatment and management of T2D to ensure safe and evidence-based practices. On the contrary, the effectiveness of many of the traditional remedies is not verified by precise scientific evidence. Moreover, biomedical knowledge remains dominant over traditional beliefs in the contemporary health system, especially in Western countries, including the UK. Nonetheless, there is the need for a stronger regulation for traditional remedies to improve

safety, quality control and effectiveness of the traditional medicinal products essential to biomedical care (WHO, 2013b; Wang and Xu, 2014). WHO (2013b) strategies for traditional medicine emphasise creating fundamental policies, for improving accessibility, quality, efficacy, and safety of traditional medicines and creating a knowledge-based system for the utilization of traditional medicines. Developing and implementing policies, guidelines and regulations that reflect local and cultural needs are essential for the incorporation of traditional healing systems and knowledge within biomedical care and treatment of T2D.

Religious beliefs and spirituality

Another significant finding from the study was that prayer and spirituality were considered as an alternative and important way of effectively controlling and managing their T2D. The study found that the majority of BsSAs have a belief in God and practice either the Christian or Muslim faith. The majority of the study participants with T2D prayed for their overall emotional, psychological and physical well-being, as well as some praying specifically for the cure of their T2D and other illnesses. Prayer was considered complementary to the use of prescribed medications and making positive decisions about dietary and lifestyle changes. Many of the study participants believed that it is important to rely completely on God for complete healing even with the use of other prescribed medications or traditional/alternative remedies. They believed that a combination of prayer, diets and other remedies would provide them with complete health and could eventually cure their diabetes. Four of the participants with T2D using alternative remedies only to treat the T2D also believed that prayer was a major component of their diabetes management. These findings contrast the findings from Wilkinson et al. (2014a) study, which reported that the spiritual beliefs about the outcome of diabetes being in God's hands has a negative impact on diabetes management. In this study, prayer was seen by the participants as a strategy for coping with the stress of

managing fear, struggle and the impact of T2D, and its related complications daily. This finding of the significance of prayer, faith and religious belief as a coping strategy for the management of T2D and its related complications was also found in the other studies with participants diagnosed with T2D in the UK (Scott, 1998; Brown et al., 2007; Grace et al., 2008; Darr et al., 2008, Lawton et al., 2008; Greenhalgh et al., 2011; Kohinor et al., 2011; Patel et al., 2015; Bashir et al., 2016) and outside the UK (Polzer and Miles, 2007; Schoenberg et al., 2009; Casarez et al., 2010). Participant's narratives in this study revealed the positive connection between spirituality and diabetes self-management behaviours. This can, however, be attributed to high religious belief and practices among African communities in a secular society. Again, understanding this connection and relationship with spirituality and beliefs among the BsSA communities could create opportunities for easy access to the communities by HCPs for health promotion.

Concepts of healing

The study also points to the concepts of healing that emerged from the narratives of the study participants with T2D. One aspect of this study that adds knowledge to the role of cultural beliefs on diabetes self-management is the way BsSAs conceptualised the knowledge of healing through a holistic approach to health. This study found that a holistic approach to diabetes management promotes positive health perception and supports participants' healthy lifestyle decision and choices of treatment. Many of the study participants with T2D acknowledge the use of alternative remedies more as a way of promoting healing compared to the use of medical treatment, which only helps them to treat symptoms or prevent complications. The majority of the study participants emphasised the term 'healing' when talking about the use of alternative remedies, observing their health at different levels of well-being (emotional, spiritual, psychosocial, physical and mental). Some of the study

participants (BsSAs) claim to alter their medical treatment and place a higher priority on other remedies to speed up their healing process. However, only a few of the HCPs agreed to the holistic principles of some of the alternative remedies, which look beyond disease treatment. The importance of this perspective confirms the views of Kumar et al. (2006), Chang et al. (2010) and Uskul (2010); identifying the significance and importance of people's experience and how that defines their process of healing and response to treatment. However, the interpretation of healing is subjective to the individual's experience and trust in treatment or remedies.

The efficacy and value of alternative remedies, as it is increasingly valued for unconventional treatment for diabetes, as mentioned above, remains unacknowledged and undervalued by most HCP because of limited scientific testing. However, this study confirms that alternative remedies are a cultural landscape of health and healing for people living with T2D but obscured behind the professionalised and medicalised processes designed for diabetes treatment from the policy perspectives. As identified from the views of the study participants, a basic distinction existed between care and healing based on knowledge and lived experience of managing diabetes. The findings from this study and other studies on the prevalent use of alternative and traditional medicines among the BsSA communities (see figure 6.2) have shown that HCPs and other researchers need to be more aware of the significance of non-biomedical interventions in diabetes care and management (Balde et al., 2006; Ogbera et al., 2010; Keter and Mutiso, 2012). Moreover, beliefs and practices around the use of traditional medicine as an 'alternative' to conventional medicines, used by the respondents reflect the concerns about the medicalised approach to the treatment and management of T2D. Therefore, this study suggests an understanding of the sociocultural contexts and the healing process within which the use of alternative remedies is inextricably

linked to an improved health outcome. Individuals interpret their experiences in the use of alternative remedies based on their lay belief system. This allows an opened discussion for a non-medicalised explanation of diabetes treatment and management, as opposed to the treatment compliance and the medicalisation of diabetes from the diabetes policy perspectives.

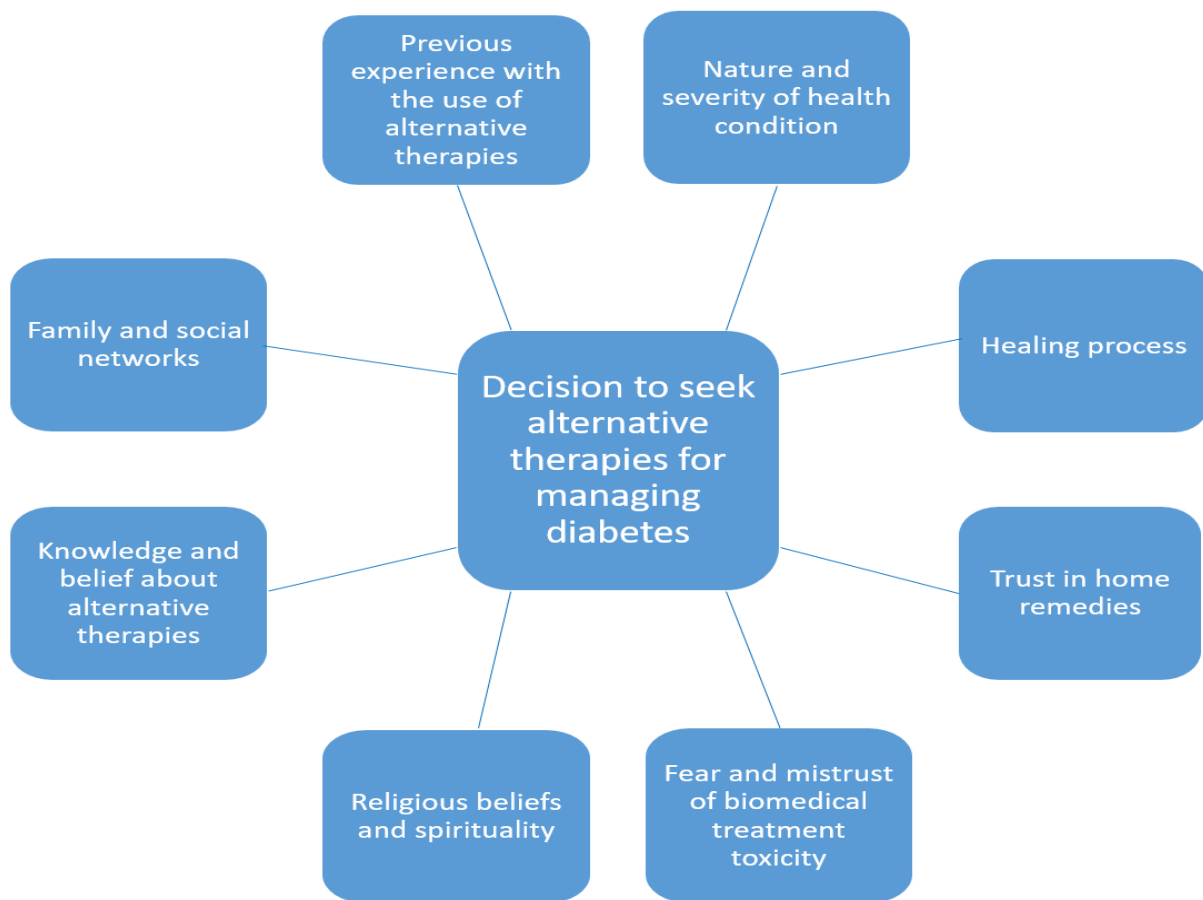


Figure 6.1. Summary of identified factors (from the study findings) impacting on the decision to seek alternative therapies among the BsSA communities

Figure 6.1 above shows a summary of the identified factors influencing the decisions of BsSA communities to seek after the use of traditional and alternative remedies for managing

T2D. This diagram shows the collective mentality and community approach to seeking and accepting treatments, which exist among the BsSA communities.

6.3.3. Relationship between HCPs and BsSAs with T2D (Theme 5.3. and 5.5)

Interaction with HCPs

The study described the nature of the challenges that BsSAs with T2D faces with their HCPs and vice versa in the provision of diabetes care, initiation of treatment regimens, health information and management of diabetes diagnosis. HCPs described how culture influences the way people from the BsSA communities understood diabetes and the related risks and integration with HCPs. HCPs reported many BsSAs diagnosed with T2D do not come back after diagnosis or keep their medical appointments unless they are at risk of complications. There were phrases used by some of the participants to illustrate this; “...*I hardly go to the GP anymore unless if I don't feel well...*” (see theme 5.5.6, BALWD#1), “...*It has become a cultural thing, that they only come for treatment or any other diagnosis only if they have pains or have concerned symptoms they become worried about. They don't bother if there are no further symptoms, forgetting that some of the risks we tell them are progressive...*” (see 5.5.1, PRC3Dr). The interaction with BsSAs living with T2D was described as utmost for improved health and self-management behaviours. These findings were consistent with Polonsky et al. (2010) and Bundesmann and Kaplowitz (2011) study on the significance of the positive interaction between HCPs and their service users and how it helps to improve health outcomes and reduces the risk of complication.

However study participants with T2D reported that the challenges of interacting with HCPs, low attendance to recommended diabetes programmes and poor adherence to medical treatments were due to anxiety, cultural values for natural and other alternative remedies,

family commitments, beliefs, lack of adequate information from HCPs and mistrust of biomedical treatments. Other challenges associated with the way study participants with T2D manage their diabetes were reported to emanate from the nature of the health care system and the medicalised nature of treatment. For example, many of the study participants with T2D reported that the care and treatment regimens provided by some HCPs were not ‘user-friendly’ or ‘culturally sensitive’ especially for African diets pattern and food choice, beliefs and lifestyle, hence putting off some people from using or adhering to the offered services. These challenges further resulted in some participants seeking alternative remedies whose services they considered culturally sensitive, accessible and user-friendly. Lack of positive interaction prevents HCPs from meeting other unexpressed needs of their service users that could be culturally ingrained (Wilkinson et al., 2014a). This study found similar views expressed by many of the study participants on how HCPs seemed not to meet their health and social needs fully. This finding reflects the findings from Zamanzede et al. (2015), concluding that the provision of holistic care increases the level of understanding of HCPs about their patients and their needs.

Poor level of information from HCPs

When discussing the impact of the relationship between BsSAs living with T2D and HCPs, responses showed the poor level of information from HCPs. According to the study participants with T2D, the poor level of information provided by their HCPs made it more challenging to self-manage their diabetes. It makes them primarily reliant on medical care and treatment, including participating in diabetes programmes. Previous studies such as Nam et al. (2011), Greenhalgh et al. (2011), Kohinor et al. (2011) and Shrivastava et al. (2013) indicate how greatly the information from HCPs influence people’s health behaviours. Many of the participants with T2D reported that some of the information provided by HCPs is too

vague and scientific (see 5.5.6), which is the reason why some of the participants turn to the use of alternative remedies. This has been described in other studies as a major barrier to seeking medical treatment after diabetes diagnosis (Chinenye and Ogbera, 2013; Zamanzede et al. (2015).

Additionally, many of the study participants with T2D felt they are being left alone to manage their diabetes once HCPs provide them with basic information. This finding reflects the findings from Hinder and Greenhalgh (2012) study, which concluded that people with diabetes spend a larger percentage of their time managing their diabetes on their own with just a little or basic information from their HCPs. Other studies have also noted conflicting priorities on the provision of information between HCPs and people living with T2D. Some of the study participants with T2D also reported that while they focus more on the immediate impact of their diabetes on their quality of life and other aspect of their lives, HCPs tend to focus more treatment, reducing the risk of diabetes-related complications, and perceive cultural beliefs as a major barrier for a healthy lifestyle. This lay-expert belief system that is culturally detached cannot be ignored in the care process for improved health outcomes of people living with T2D. HCPs should be willing to offer more than just prescriptions and treatment recommendations. It is important for HCPs to understand and be sensitive to the cultural and social challenges faced by people living with T2D while managing their condition. Culture and social commitments are the essence of the identity of people from the BsSA communities, but they should not be dismissed as a barrier and/or explanation for ineffective and inefficient self-management of diabetes.

6.3.4. The silenced voices - professional dominance on diabetes care (Theme 5.3, 5.4 and 5.5)

Acceptance of diagnosis (BsSAs with T2D)

The study participants with T2D felt they were required by HCPs to accept the diagnosis and respond to the impact of diabetes care in order to be able to cope with other demands from their families, their communities and the society. The nature of the coping strategies within the biomedical diagnosis of T2D shared by the participants ranged from acceptance of illness and passive resistance to the impact of diabetes on their daily lives. This finding is consistent with the arguments of Keszthelyi and Blasszauer (2009) and Mulgan (2010) describing the implications of HCPs telling people what to do and how to manage their health, which could also further result in people's unwillingness to change behaviours due to cultural identity and norms. The passive resistance could result from participants been faced with the challenge of carrying out required health behaviours in different social situations or cultural environment. However, these coping strategies had direct implications for their self-management and health-seeking behaviours. The study participants with T2D highlighted family commitments and other social obligation is central to their lives and therefore are bound to accept their diagnosis and remain resilient to seeking acceptable care and treatments in order to be able to manage with other affairs of life. Acceptance of cultural norms becomes an option for coping mechanism, which further explains the role of religion and the use of alternative and/or traditional remedies in self-managing diabetes. The strength of faith, belief in religious and spiritual leaders, and also the use of alternative remedies (as previously discussed in 6.3.2) described by the BsSA participants with T2D, appeared to have prompted some of them to follow the instructions of their religious leaders over advice from HCPs. This finding is consistent with the findings of Grace et al. (2008), Green and Tones (2010) Ofori and Unachukwu (2014) identifying the various mechanisms underpinning the involvement of

people at every level of care to reflect other social and cultural context of their health and illness that could support healthy behaviours.

The professionalisation of the healthcare system (BsSAs with T2D and HCPs)

The discussions with both the study participants with T2D and HCPs also revealed some of the tensions inherent in the issues raised, particularly about the power and dynamics of the professionalisation of the healthcare system. For example, some of the BsSA participants with T2D felt that discussing the power dynamics in the healthcare system could not be challenged; depicting HCPs' advice and biomedical representation of diabetes as dominant and oppressive of their cultural identity. There are some phrases used by the study participants to illustrate this argument; "...*My husband uses this word... that I'm too scientific with my health, you know, it's all about what science and that's what your doctor tells you... yeah, exactly, he does not understand fully what could go wrong if I don't manage my diabetes (see 5.5.6, BALWD#5), "...The information they provide to you is too systematic and scientific"* (see 5.3.2, BALWD#23). Many of the study participants argued that this professional representation only encourages people from outside the communities to view most of the cultural values, diets and lifestyle of the people from the BsSA community as being unhealthy. These were also tied up with a feeling that most of the advice and opinions of the people are disregarded by HCPs, and their cultural knowledge dismissed. Some explanation of these concerns is also found in other studies that show that professional dominance has an intimidating and often alienating effect on people's decision to seek biomedical care (Nettleton, 2013), as opposed to seeking alternative and/or traditional remedies and vice versa (Schoenberg et al., 2009; Uskul, 2010; Kwam, 2012). Schoenberg et al. (2009) and Kham (2012) also demonstrated that medical representations of illness and the biomedical dominance of individuals' lived experiences of health were significant challenges

to Black African community's acceptance of healthcare services that are not able to speak to them. Similarly, few of the HCPs who took part in the study recognised the impact of the medicalisation of diabetes care and felt that there was a need to understand and accept the contribution of people's opinions on their options of care to improve health outcomes in the communities. These findings support the argument from Taylor (2007), and Nettleton (2013) that lay knowledge and shared lived experiences is of key value and importance to inform health interventions that can promote positive health outcomes and behavioural change. It is necessary to recognise from this study that the way diabetes treatment is being medicalised and presented to people living with the condition silences their own lived experiences.

These findings revealed the perception and understanding of professional knowledge and its dominance and the implication of overpowering people's right to health. The silent discrediting of cultural and lay knowledge and the implications of delayed access to care and management of the disease equally influence the decision to seek alternative care. It is worthwhile stressing the importance of understanding health decisions that are grounded in people's culture and how it motivates people to self-manage their diabetes effectively. For example, dietary advice and treatment information should not be completely medical prescriptive, but negotiable and culturally sensitive. The findings from this study show the need to consider the importance of cultural food and beliefs within the individual's social, cultural and environmental context. This is clearly identified in the findings from other studies (Brown et al., 2007; Esposito et al., 2010; Carr, 2012; Harrison, 2014; Patel et al., 2015). This inclusion will not only increase the complexity of diabetes care and management, but it also creates opportunities for enhancing continuity of care and self-management behaviours of people from the communities. However, the nature of the professionalisation of health professions, in terms of status, hierarchy, qualifications and specialities, puts a distance

between HCPs and the communities. Moreover, it holds on the debates on power and shifts on who holds the knowledge and the delineating professional boundaries based on expert knowledge (Saks, 2012; Nettleton 2013). HCPs need to communicate beyond clinical perspective by understanding communities grounded in culture and collective identity in order to achieve positive outcomes from the intervention provided to the communities.

The issue of HCPs' cultural competency and disempowerment (BsSAs with T2D and HCPs)

Interestingly, some of the HCPs confirmed that they did not think existing cultural training equips them with the appropriate cultural skills in understanding the different cultural approaches and strategies for managing health issues and behaviours that are culturally grounded. HCPs felt that they are often being disempowered when it comes to cross-cultural communications within a medical approach, resulting in complexity in diabetes care and provision of vague information to service users. Examples of such illustrations are; *"...I became confused because the patient information reads Black African and I just thought they are all the same. That was really the end of the discussion about food because I became aware that this man's cultural diet is definitely not part of the information I had at hand"* (see 5.5.5, PRC1Nt), *"... It just makes you feel so helpless, doesn't it? You wonder what else is left for you to know...you come across many things in different ways, at different times with different people"* (see 5.5.5, PRC3Nu). The HCPs also felt that revealing such concerns pitted their professionalism against their healthcare practices. However, these findings raised a very important point about the impact of the quality and the reliability of services provided to people living with T2D from culturally grounded communities. Many of the study participants with T2D also felt some of the HCPs are not empowered and equipped with appropriate cultural skills and religious knowledge. They (BsSAs living with T2D) however,

choose to be silent about their feelings concerning service delivery because they believe challenging HCPs could negatively impact their lives and that of their communities. These findings differ from previous findings reported by Bashir et al. (2016) study, which described that people were mainly satisfied with HCPs' understanding of religious and cultural needs. Bashir et al. (2016) findings seem to attribute the knowledge concerns to a basic understanding of these needs. At the time of this study, it appears that silence among HCPs about disempowerment in the provision of culturally sensitive diabetes care is rarely discussed in the literature of health behaviours of ethnic minority communities. This points to a potential area for future research.

There was also concern by some of the study participants from the BsSA communities who felt that their opinion is often silently discredited on many occasions due to HCP not being provided with necessary cultural skills. They believed that the lack of provisions of the culturally sensitive framework for diabetes care to HCPs made them vulnerable to silent discrediting. Some of the study participants indicated their pre-conceived ideas of HCPs seeing their diagnosis was because of their individual unhealthy lifestyle. This again raised their anxiety each time they attend clinic appointments, perceiving that HCPs judge them based on their African diet and lifestyle. This made some of the study participants with T2D defensive about their diets and cultural lifestyles in order to manage the felt stigma that they were experiencing. However, the study participants with T2D also commented that it could be very difficult to hold the HCPs responsible for cultural incompetence as many are obligated and bound within their medical approach to provide services and care available to them. It became apparent that through perceived silent discrediting and HCPs disempowerment, some of the study participants from the BsSA communities felt a loss of confidence in the information provided to them by HCPs.

The HCPs that participated in the study felt that culture is a dynamic phenomenon and health policies for diabetes care should improve training on cultural competency for HCPs to facilitate understanding between them [HCPs] and people from the BsSA communities. They felt this approach would improve their professional skills, cultural knowledge and attitudes of other HCPs. This enables them to effectively handle cross-cultural situations, thereby improving health-related outcomes for people from ethnic minority groups like the BsSA communities. The available literature asserts that cultural competency of HCPs is essential for reducing disparities and achieving positive health outcomes for people living with T2D (Phillips et al., 2012; Zeh et al., 2016). These findings also supported Nazroo et al. (2008) and Khanna et al. (2009) study identifying the importance of understanding sociocultural inequalities that could further create opportunities for professional skills development and cultural awareness. These findings are also consistent the other studies suggesting an integrative and collaborative intervention programme that allows HCPs to provide consistent information and practical skills to PLWD (Greenhalgh et al., 2011; Hastings and Chandler, 2015)

HCPs also felt that it is challenging that the BsSA communities comprise of different nations and cultures. They felt it was difficult to master the various cultures and be able to address all the cultural needs of managing diabetes. However, there are many notable similarities in the cultures of these communities that can assist HCPs to effectively address specific cultural needs of the communities, particularly taking into consideration the collective mentality and approach to seeking treatments, similar diet patterns and social lifestyle.

6.3.5. Community networks as gatekeepers and drivers of health outcomes among the BsSA communities (Theme 5.4 and 5.6)

The findings from the study suggest that the engagement of HCPs with BsSA communities through community networks within the communities could facilitate the delivery of effective health programmes for people living with T2D. Community networks are reported as key gateways to building trust and increasing the acceptance of specific diabetes programmes designed for these communities. This is evident in this study because accessing study participants for interviews, especially the people living with T2D was accomplished through community networks such as faith and community organisations, African stores and restaurants, self-help and support groups that are community-based and families and/or friends. This study highlights the important role community networks may play in diabetes self-management and health-seeking behaviours by acting as an existing and a potential source of health promotion and enhancement of healthy behaviours.

The consensus among study participants with T2D for a culturally sensitive intervention suitable for all their cultural and social needs highlights the importance of channelling diabetes programmes through community networks. They can provide different services, so that people living with T2D can be easily engaged, thereby building confidence, trust and providing easy access to the healthcare system. Although few of the policymakers (PLMs) were concerned about healthcare practice saturation; *“We always have been willing to take on more and more stuff to improve the health care provided to people living with diabetes, but we also need to be careful of getting our services saturated. The question is how many cultural kinds of stuff are we going to put on board”* (see 5.6.2, PLM1), many acknowledged the importance of community network as a platform for reducing the fragmentation of diabetes care and improved cultural skills for HCPs. The study findings confirm the

significance of collaborative care for increasing cooperation and knowledge sharing among GPs, local authorities and community services. Community networks were identified as a platform for accessing and distributing of health information and activities that could promote diabetes care and provision of culturally sensitive programmes.

The study participants with T2D and policymakers interviewed for the study felt that the community network process could help to identify current and potential resources that are or could be available to people with diabetes within the BsSA communities. This also included identifying sources of healthy food (African food stores) and gatekeepers that are available to people from the communities. As the importance of the local food to cultural identity for people of African origin has gained traction, studies have provided evidence that increased access to healthy and nutritious local food, is associated with lower rates of obesity, which is an important risk factor for T2D (Powell et al., 2007). Access to healthy and nutritious food is also especially important to the African communities, given its ethnic composition is heavily influenced by cultural and traditional diets. Although healthier foods could be less available in certain African stores, other studies have suggested that targeting availability may offer capacity for policy initiatives that could provide access to larger African stores that can offer affordable prices for healthier foods (Lewis et al., 2011; Krukowski et al., 2017). This may also provide other avenues for enhancing food environments that could lower diabetes and obesity risk.

During the interviews, participants with T2D, HCPs and PLM were asked about the resources for diabetes care that may be available in the community for people with diabetes. Neither the HCPs nor PLMs interviewed could identify culturally friendly resources for diabetes care outside those within the medical framework recommended and managed by the NHS.

However, when the study participants were asked to identify resources available outside the NHS that could support their diabetes management, many suggested that building support groups through networks that are community driven and collaborating with faith organisation could help promote healthy self-management behaviours. Interestingly, this was something that could not be confirmed by either the HCPs or PLMs during the interviews, as an existing or future strategy for diabetes intervention. However, when the HCPs and PLMs were asked at the end of the interview to suggest any other contributions to the study, they suggested that a collaborative practice with African community networks could strength diabetes care and management services for the communities. Further research is therefore needed to explore our understanding of the community networks and support groups that could sustain positive self-management behaviours among the BsSA and other ethnic communities. Previous studies have also indicated that effective self-care management behaviours can only be achieved when people are empowered with the skills and knowledge to manage their condition (Rubin et al., 1989; Nguma, 2010). Community networks have therefore been identified from this study as one of the channels through which people from the BsSA community can be provided with the right skills and knowledge for managing their T2D.

6.4. Implication of study

6.4.1. The implication for diabetes policy

Advances have been made in diabetes care through integrating and understanding of medical treatments, especially with the advancement in technology and scientific knowledge of the nature of diseases, forming the basis of much diabetes care provision. The growing trend for a personalised approach to diabetes care is most evident from the way in which programmes and treatment regimens that claim to suit the individual health needs are being shaped by

medical ideas whilst the lived experiences of individuals are being excluded in the management process (Coulter et al., 2013). However, personalised approaches impede the comparative nature of how health behaviours and practices are acted out as part of everyday life in complex social and cultural context (Freund et al., 2003; Uskul, 2010). Moreover, the clinical representation of diabetes tends to widen the inequality gap between medical knowledge and traditional knowledge among the BsSA community. HCPs should be aware of the cultural and religious beliefs that may either modify or alter self-management behaviours because of biased clinical perceptions of illness and symptoms. The way of thinking about people and illness goes beyond the current medical paradigm of illness in order to understand, at a deeper level, how other factors affect our health and decisions on which care to seek. The process of getting well, from the BsSAs's perspectives, means looking at a whole range of factors in a person's life: their experiences, lifestyle, relationship with others, cultural values, culturally appropriate advice and activities that have importance in an individual's life. The findings of this study provided insights into the role of culture and health beliefs on self-management behaviours, which reiterate the call for new cultural knowledge and approaches to guide health practices. It is now known that the provision of culturally congruent care and diabetes interventions involves much more than the scientific understanding of the illness and dietary preferences. This research can, therefore, guide the development of interventions and education programmes that utilise culturally appropriate methods, to enhance diabetes care provision for people from the BsSA communities.

While policies have been put in place to develop a culturally competent practice, the questions remain about the best way to encourage a change in the attitude of HCPs to BsSA communities. The lack of policy frameworks for culturally congruent diabetes care is partly explained by limited levels of cultural information and lack of cultural awareness that could

support the need for such frameworks among HCPs. This study's findings are therefore an important source of information for policy formulation as well as programme interventions aimed to provide suitable care for people with diabetes whilst empowering HCPs with cultural skills. There is the need for HCPs to be trained with practical skills for cultural awareness and sensitivities to cultural practices, which is an important component of cultural competence for providing adequate health care. They do not necessarily need to have deep or complete knowledge of all the various cultures exhibited by people from the BsSA communities, but their approach should be one of an openness and a willingness to learn about the culture of the person receiving their service. It is about looking beyond the illness and providing care to a person. This study has shown that the majority of the people from the BsSA communities seek healthcare and diabetes management from natural remedies, traditional diets, the experience of friends and families and religion. While there may be similarities between BsSA and other BME communities such as the African Caribbean and South Asians, it should be acknowledged that there are yet other cultural differences that exist among them. It is equally essential that HCPs understand that bringing the community into the intervention process could improve self-management behaviours among the community. Netto et al. (2010) emphasised that the conceptual basis for health intervention needs to match that of the community. In other words, the intervention for diabetes care and improved self-management behaviours needs to be immersed in people's culture, identity and beliefs from inception; attending to needs as expressed by members of the community and delivered through that community. Empowering and educating people with T2D about healthy lifestyles and providing policymakers with sufficient information for informed diabetes policies could help in the improvement of health outcomes, benefiting both the service providers and service users (Coulter et al, 2013). Figure 6.3. highlights below the proposed culturally sensitive framework that could bring lay people with T2D into the policy

process so that their cultural beliefs and perspectives can really drive the process for diabetes intervention.

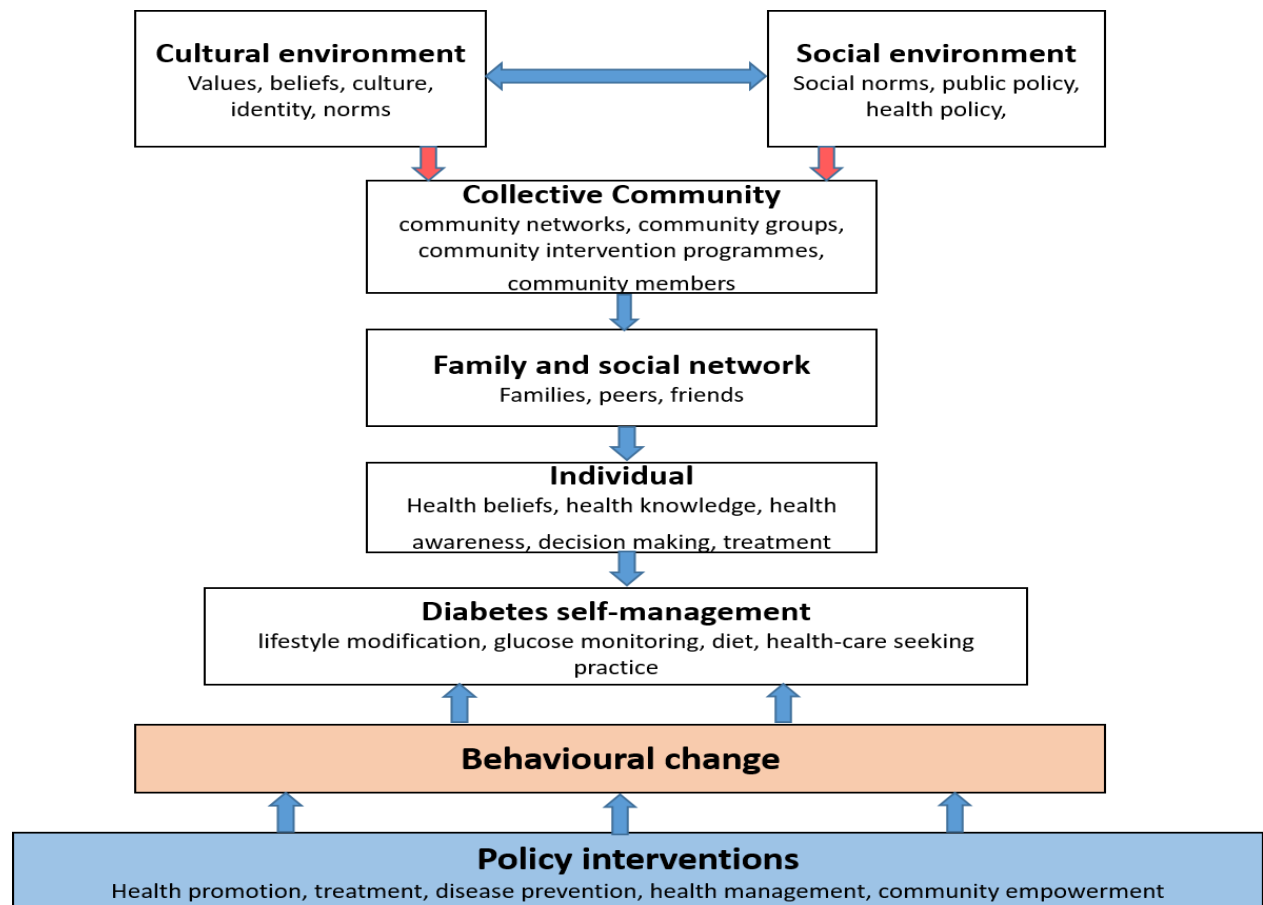


Figure 6.2. Culturally sensitive framework (Adapted from Jack et al., 2004 multilevel intervention for diabetes self-management)

Effective advocacy for a culturally sensitive policy framework also needs to understand the drivers of self-management behaviours and health-seeking practices among people with T2D in an increasingly treatment pluralistic community (i.e. the use of both alternative and/or traditional and biomedical treatment for managing diabetes). As identified in this study, the use of both traditional and biomedical treatment by the people living with T2D and/or the commercialisation of its efficacy has become a common practice among the BsSA

communities. This suggests that cultural beliefs and the use of traditional medicine will continue to play a significant role in the treatment and management of diabetes among these communities. A policy review should acknowledge the efficacy of some of the alternative and/or traditional remedies and provide guidelines for the development of modalities for integrating more of these alternative services into the biomedical care system and promotion of community-oriented programmes to ensure quality care and management of diabetes in the UK (Green and Tones, 2010; Oyewole, 2011). This system of care has been proven effective in other countries like Cuba, China, India and Nigeria, and even more broadly as complementary medicine (Appelbaum et al., 2008; Oliver, 2013). This study, therefore, identified the significance of understanding the cultural dimension of health and treatment choices for diabetes care.

6.4.2. The implication for community mobilisation

The findings of this study provide substantial evidence in support of the need for future research on community empowerment for innovative care that addresses social-cultural practices and needs for improving diabetes care among a high-risk population. The study proposes a sociocultural framework that can be studied further and promotes the importance of ethnographic approaches for engaging and empowering communities in health intervention, disease prevention and the research process.

The drive behind this study was to identify the positive role of culture on health behaviours and develop an approach that could enhance the community empowerment through the access to and provision of diabetes care. One of the most profound findings of this study is the identification of the underlying concepts of healing as a driver for health-seeking behaviours among the communities. Thus, this study introduced a potential theory (PEN-3 model) that

could help practitioners and policy-makers understand better, how the development of norms and identity that control relationships within a community could be evaluated to ensure effective integration of community actors in health intervention programmes (see 3.6.2). It will be important for community stakeholders and policymakers to not only design health intervention programs that encourage individual responsibility, but also those that can improve the social environment through community empowerment and development (Eckersley, 2006; Airhihenbuwa et al., 2009; Iwelunmor et al., 2014). According to Eckersley (2006) and Sanderson (2013), this approach helps to promote a collective sense of inclusion with the communities. It is important to recognise the integrating of social and cultural actors that can work together to develop strategies and programmes for inclusive practice. This could promote improvement in self-management behaviours and health awareness among the communities. Empowered communities could assist in delivering a range of health-oriented services, for example, healthy African food initiatives among African stores, exercise and recreational activities in social events, mental health support for people struggling with stigma and discrimination, and many others. Community participation could simultaneously increase their sense of responsibility, ownership and awareness of diabetes intervention programmes. Moreover, this study has presented an original and neutral way of the engaging community to explore diabetes as a significant public health issue. It also contributes to the advancement of community-based research for diabetes care and management.

Concentrating on the social construction of diabetes and health seeking practices could enable HCPs to consider the wider underlying determinants normally unaccounted for in the traditional health needs assessment. Such information would add value to the work of professionals when they are dealing with BsSA communities in relation to diabetes care and health-seeking behaviour. The framework for diabetes care in England acknowledges the

impact of culture, religion and beliefs in the social scripting of diabetes self-management behaviours. Previously, there was a little importance placed on these interpersonal factors leading to a lack of awareness of social and cultural significance to health behaviours. Heeding them, however, enhances inclusiveness and benefits the local population in line with the sociocultural framework underpinning this study. It advocates the need to promote research, which is of use to the research participants and their communities (Sanderson, 2010; Uskul, 2010).

The designing of community-led interpersonal health information sources/centres that use existing community networks and audio-visual materials associated with specific ethnic minority populations' cultural beliefs could promote positive self-management behaviours and community engagement in health programmes. However, future research should be aimed at investigating the effectiveness of such initiatives in promoting service utilisation and positive diabetes self-management behaviours. Future research could explore a way of developing relationships that would actively integrate community actors in the diabetes care process to build the capacity of health services through community networks.

6.5. Research contribution

This study has contributed to knowledge and theoretical contribution for both present and future research. The contribution that this study has made are discussed in the following subsections.

6.5.1. Contribution to knowledge

The main contribution of this study is that it expands the knowledge of the significant role and underlying principles of cultural values and beliefs on T2D self-management behaviours among BsSA communities. Exploration of cultural influences and significances on T2D self-management in these cultural groups enhance the knowledge and understanding of the unique needs of individuals in this population. It is widely known that BsSA communities are disproportionately represented in diabetes statistics across the UK because most data are mainly a representation of Black Caribbean communities and South Asians. Furthermore, there is also evidence from other studies and findings from this study to show that most individuals from the BsSA communities present late for diagnosis and treatment owing to cultural issues. This is an important contribution to diabetes care, especially given that the increasing prevalence of T2D among these ethnic minority groups (BsSAs) and the obstacles to effective care that they face. Besides, this study identifies discrepancies between the self-management needs and expectations of people living with T2D, and existing self-management support provision. In reporting on the experiences and perceptions of BsSAs with T2D, the findings highlighted the overarching problems within clinical practice, BsSA cultural practices and health service delivery among these communities. The study findings emphasise the need for greater cultural sensitivity and awareness among HCPs in the UK and the need for a provision of culturally relevant information to improve health outcomes and self-management behaviours among these communities. The findings provided insight into the future development of policies and programmes that can be community-driven and can facilitate the provision of culturally congruent care for BsSAs living with T2D.

The BsSA communities have shown an increasing knowledge and understanding of the benefits of a healthy diet and lifestyle, and the implications of these on their health outcomes

and prevention of diabetes-related complications. Despite this, however, the study findings showed that there remains a significant amount of uncertainty about what is emerging from society in terms of lifestyle changes; mainly about diets and alternative treatments. In other words, knowledge is not being translated into action due to the wide range of internal and external factors influencing health decisions. The uniqueness of community identity has reinforced the fact that the changing face of public health should away from being just about medicines and treatment to a holistic and ecological approach that recognises that health determinants are complex; occurring at both an individual and societal level. Evidence from this study suggests that knowledge alone cannot offset the negative social and cultural trends influencing health decisions, as seen among the BsSA communities.

6.5.2. Theoretical contribution to the study

The conceptual framework underpinning this study is the sociocultural model adopted from Sanderson (2010) and the modified Mcleroy et al.'s (1988) socioecological framework for health promotion, which has been previously discussed in-depth in chapter 2 of this thesis (see 2.7.3). The theoretical approaches were chosen based on its suitability for reassessing sensitive cultural values and issues associated with diabetes care and management. Hence, the study findings provided actual evidence that underpins these theoretical approaches. The framework is defined by its practical effects of identifying the intersections between culture and the different modifying factors that influence self-management behaviours among BsSA communities and its interpretations from the service providers (HCP and PLMs). People think differently about their culture and belief, and how that influences their health behaviours. Therefore, this study emphasises on the importance of how listening the voices of people whose health and self-management behaviours are culturally embedded, foster new understanding of diabetes management and how these group of people can be empowered for

improved health behaviours. This encouraged the BsSA communities, HCPs and policymakers interviewed for the study to recognise the practical effect of community togetherness, contested cultural issues related to diabetes care at different ecological levels of health promotion, and their significance to self-management behaviours and health outcomes.

It was identified from the literature review that prior qualitative and quantitative research has commonly looked at the experience and life trajectory of people from the African descent living with T2D and has investigated their adherence to treatment and self-management regimens. This study, however, contributed a new dimension of understanding the role of cultural beliefs by providing evidence on the lay perceptions and experience of living with T2D. It highlights the limited involvement of HCPs, particularly doctors and diabetes educators in self-management support provision. This study also provided evidence that, despite poor adherence to treatment and self-care, people from the BsSA communities have a positive perception of the practice of self-management, though their self-management practices were found to be limited and influenced by cultural and social factors that are beyond their control. Furthermore, this study's theoretical approaches provide valuable evidence that illuminates the discrepancies between people's cultural needs and the support provided by comparing the views of people with T2D, multifaceted HCPs, and the real clinical situation. The conclusion of this study was drawn from a holistic understanding of these realities. Three key issues were identified in this study: discrepancies between the self-management needs of Black Africans and the support provided, traditional medical model vs patient-centred care and role of cultural values offer insight into reasons for lack of engagement with self-care of T2D, and social stigma among Black African communities, which have not previously been reported. The study findings, therefore, provide evidence that

sociocultural models can be useful in understanding and predicting self-management and health-seeking behaviours.

In addition, this study contributes to the literature on the sociocultural framework of operationalising cultural and behavioural theories beyond individualised approach to study the cultural beliefs about diabetes care and health seeking practices of people from the BsSA communities. Modifying factors such as individual factors and interpersonal factors have played a crucial role in the self-management of T2D among the communities. The study findings that these communities share a cultural belief model about T2D management supports and strengthen the validity of the study. The research has shown that using an established theory like the PEN-3 public health cultural model can be applied to diabetes care (see 3.6.2). This is because this model moves beyond the individualistic approach applied within the medical intervention for diabetes care and centralises culture and community collectiveness in the development of health promotion intervention (Airhihenbuwa and Webster, 2004). Taking a theory-based approach enables the creation of a replicable methodology for identifying sociocultural factors that predict self-management behaviours. Furthermore, due to the informal approaches underpinning this model, HCPs could provide self-management support that goes beyond providing individualised medical information and develop problem-solving skills that could promote the application of cultural knowledge and collective community identities to diabetes intervention. The sociocultural context of this model further gives an opportunity for community-driven interventions, as opposed to people remaining only as recipients of professional-led intervention for diabetes care.

Furthermore, the cultural framework within the methodological approach used in this study provided the researcher with an opportunity of positioning herself as both an insider and

outsider of the studied community in order to be able to explore the perspectives of the research participants. This allows the flexibility and uniqueness of the study in uncovering and acknowledging the collective sense and togetherness observed within the studied communities, which may encourage community participation in future studies. This study, therefore, recommends the collective sense of a community as a major perspective to be considered when studying the cultural impact on health behaviours. This may ensure that the complete community knowledge and cultural identities are acknowledged in all future related researches involving ethnic minority communities.

6.6. Strength and limitations of the study

This research has several strengths, which has contributed uniquely to the knowledge about the role of culture in health seeking practices and self-management behaviours among BsSAs living with T2D. However, there were also a few limitations identified in the study.

6.6.1. Research Methodology

As stated earlier in the literature review, information on the significance of culture on self-management behaviours among the BsSA communities is limited. At the time of writing this thesis, this is the first ethnographic study looking at the significance of cultural beliefs on diabetes self-management, which further identifies the health-seeking practices of Black Africans living with T2D. This study provides deep insight into the fundamental knowledge of diabetes self-management behaviours in the context of cultural experiences, and it provides an understanding of health-seeking practices among the BsSA communities. This information will be vital in the development of culturally sensitive initiatives for diabetes

care and management. Moreover, the information will be critical for future research and policy formulation.

It is important to note that all study participants with T2D were of Black sub-Saharan African descent. Conversely, the strength of this study lies in its methodology (e.g. ethnography, qualitative, individual interviews) to explore an area of limited research among the BsSA communities in the UK. Primarily, this study provides a holistic understanding of the various factors that play significant roles in diabetes self-management and health-seeking behaviours; they are not limited to individual factors. The use of individual interviews was arguably more beneficial in terms of gaining richer and more detailed perspectives from both the service users (BsSAs with T2D) and service providers (HCPs and Policymakers) experiences in contrast to the quantitative methodology. The researcher's cultural identity as a Black African living in Nottingham facilitated identification of these communities and access to them within the city. This has been previously discussed in detail in chapter 4 of this thesis (4.3.3.3).

The triangulation of the information generated from different sources of data provides internal validity and reliability of the data collected for the study (Patton (2002). Additionally, triangulation of the data analysis process was achieved through the sharing of emerging themes with both study participants and supervisors to reduce biases that might have arisen during data analysis and increase credibility, verification and validity of the study.

Although the methods of data collection used for this study were viewed as the most appropriate, adoption of other methods of data collection like quantitative methods could have been utilised to cover a larger number of participants. However, the use of quantitative

method was discounted in order to be able to explore in-depth the subject under discussion and allow participants have a free and open platform to express their views on the subject (see 4.4.2 and 4.6.2)

6.6.2. Researcher as Native Researcher

Study participants are assumed, to be honest, and the study research considered trustworthy when the researcher is an insider and native of the community. The researcher being a native of an African community shows the strength of this study and its contribution to knowledge. An insider ethnographer is often expected to have easy access to information that the explored community would be unwilling to share with other researchers whom they may consider as outsiders (Jones 1970). Moreover, the native ethnographer is believed to have intimate cultural knowledge of the study population, and that familiarity with the community would result in a more accurate interpretation of cultural beliefs and practices (Streubert and Carpenter, 2011; Fetterman, 2010). However, the views of a native ethnographer as the insider versus the outsider has been criticised for failing to consider the shifting cultural identities as well as the other weaknesses that ethnographers experience when studying a familiar community (Hammersley and Atkinson, 1995; Davies, 1999) This has been previously discussed in detail in chapter 4 of this thesis (4.3.3.2).

The researcher of this study, a woman of African descent from Nigeria, was a native ethnographer sharing the ethnicity of the study population. As an insider of this study population, the researcher entered the field believing that recruiting and gathering data about cultural perspectives about T2D would not be difficult. The researcher was initially not able to recruit enthusiastic participants as many, especially the African men, were not particularly interested in committing their time for the interview. The researcher attempted to convince

the participants to cooperate in all aspects of the data collection but did not forcefully request their participation as it was voluntary and ethical. The researcher's identity as an insider (see 4.3.3.2 and 4.3.3.3) shows the strength and contribution of knowledge to the study through the access to the participants. However, the challenges that could affect the data collection process with a familiar community that is culturally sensitive to gender relations cannot be ignored (Jones 1970). There is the issue of gender inequalities among African communities, whereby African men often do not take women's ideas seriously, including lack of support and commitments. The moral judgment of an African woman and her marginalised view exacerbate the challenges a female researcher could face whilst researching a familiar community. It is therefore important that a researcher, as an insider, who is familiar to the researched community should consider these issues before conducting the research and develop potential strategies to deal with likely obstacles for an efficient data collection. Contextualising the emerging findings will avoid misrepresentation of the participant's meanings and purposes. Hence, it is important that ethnographic work conducted in health research should focus more on contextual components of the data.

6.6.3. Selection bias and sampling method

Selection bias may have occurred in this study because of the purposive and convenience-sampling strategy used to recruit the study participants. However, the selection of participants that were easy to reach was also identified as a major strength for the study because of its contribution to knowledge. Selection bias can negatively affect the internal validity of a study resulting in inaccurate generalisation and invalid conclusions about the phenomenon under study. Study participants were recruited through community channels such as churches, mosques, support groups, friends and families within the local Black African communities. Consequently, it is difficult to generalise the findings from the study participants recruited for

the study of the entire BsSA population in the UK. The sampling strategy could have been improved, and the possibility of selection bias decreased by recruiting study participants through the NHS and other networks where HCPs could encourage people from the BsSA community, who frequently receive health care service, to participate in the study. However, the channels through which the participants were recruited, especially the BsSAs living with T2D, allows the participants to be seen more as people rather than patients.

The advantage of this ethnographic study is that it helps to develop a rich understanding of a vital health issue in an unexplored cultural setting, allowing the researcher to identify a range of previously unidentified issues and the narratives behinds them. Thus, future studies can build on study findings through this ethnographic approach to develop an extensive study.

6.7. Summary

BsSAs' ability to self-manage diabetes is embedded in the social and cultural context of their lives. This study's findings highlight the need for a holistic approach that ensures personal support and community involvement in diabetes self-management. HCPs need to acknowledge the social and cultural context of diabetes self-management and identified health-seeking behaviours, as well as the supportive role played by community networks. Also, community-oriented diabetes education programmes for BsSAs with T2D might best focus on promoting supportive community channels and networks for T2D self-management within a broader social and cultural environment. These supportive channels could help initiate engagement in diabetes self-management for improved health outcome among the BsSA communities. In addition, identification of the cultural factors and belief systems that modify diabetes self-management behaviours in different ethnic groups would further improve the understanding of the unique cultural needs of individuals in diverse populations

and provide knowledge for the development of culturally sensitive intervention programmes. HCPs might benefit from exploring the cultural belief systems of the BsSA communities. The greater depth of understanding of the significance of cultural beliefs and identity may enable them to discover more effective diabetes self-care strategies.

CHAPTER 7

CONCLUSION AND RECOMMENDATION FOR FUTURE RESEARCH

7.1. Introduction

The aim of this research was to explore, and critically analyse the role of cultural factors and health beliefs on T2D self-management among BsSA communities. This qualitative research, through a conceptual and methodological approach, studied self-management and health-seeking behaviours among BsSA communities. These were investigated through their community collective culture and their individual approaches to health. More specifically, this research focused on the broader interpretation of health within a cultural context, a framework that provides an in-depth understanding of behaviours grounded in lay belief systems, lived experiences and cultural identity.

This chapter presents the summary of the study and the concluding statement. It also considers the recommendation for future research. The final section of the chapter discusses the researcher's personal reflection on the study.

7.2. Summary of study

This qualitative exploratory study revealed a range of cultural beliefs that play key roles in influencing self-management and health-seeking behaviours among BsSA communities in Nottingham. The cultural beliefs, norms, values and knowledge, central to the BsSA communities, and how these impact on health-seeking behaviours and choices of treatment were evident in interview narratives from the study participants. The lack of utilisation of this lay belief system within the mainstream health care system in the UK, however, creates disengagement with the formal health care and services. When such a situation arises, they

seek treatment from both conventional and unconventional care systems; further reflecting the impact of social-cultural factors. There was a considerable emphasis by both BsSAs living with T2D and few of the HCPs on the holistic view of health, the significance of lay knowledge, and patient-provider relationship, which are the significant features of traditional and alternative medicine. The findings from this study shed light on the cultural strengths and synergic roles of people's narratives in their healing process in achieving optimal health outcomes.

These cultural beliefs and norms from the study participants' narratives have both positive and negative outcomes of diabetes self-management behaviours. Nonetheless, the findings from the study add substantial value to the existing literature on public health issues among Black and minority ethnic (BME) groups, particularly in the choice of treatment and self-management of T2D. The contribution of this study offered qualitative support to the concept of self-management, among the BsSA communities and within the HCP community that could help them to help promote their health satisfactorily. It was identified that the scope of the knowledge of cultural beliefs and diabetes self-management was distinctive but overlapping, which shows the gaps in the level of understanding cultural practices within the public health field and the representation of diabetes within the medical model. Indeed, the findings from this study filled the identified gap in the limited scope of qualitative literature related to T2D among BsSA communities in the UK. This study findings showed that, decisions to seek care and self-manage diabetes are influenced by several sociocultural factors: individual factors (beliefs, attitude and health practice); interpersonal factors (family, friend, culture, norms, community, HCPs) and social factors (Gender, health access, utilisation of services, the nature of healthcare services).

The cultural beliefs and knowledge of diabetes among the BsSA communities reflects the dynamic cultural relationship between health and ecological succession of African beliefs. It was observed that the scope of the knowledge of culture and health beliefs was distinctive but overlapping which defines the level of understanding of self-management behaviours and health-seeking practices within the public health field. The knowledge often leads to a decision on the choice of treatment to seek diabetes care and management. Likewise, the limited level of knowledge about diabetes was reported to be a source of indirect social stigma and discrimination for the BsSAs living with T2D. More importantly, the research has shown that the self-stigmatisation of T2D is also present within the BsSA communities due to unexplained situations and cultural stigma attached to unhealthy behaviours and eating patterns by HCPs. These observations call for extensive community-level diabetes services, through social and community networks, as well as national public health and diabetes education campaigns to address ranges of factors, including the introduction of person-centred care services that would reduce social stigma and promote awareness and knowledge about T2D among the BsSA communities. Such initiatives will enhance the adoption of prevention and control measures for T2D, and health promotion programmes for early care seeking and management of this disease. This can help policymakers to develop effective, practical and personal strategies that would promote people's health and well-being and aid the prevention of other diseases.

The decision to seek medical care for many of the study participants with T2D appears to be hindered by the uncertainty of prescribed medication, lack of motivation from HCPs due to their lack of interest in certain cultural beliefs and preferences for alternative and traditional medicine. People seek treatment approaches that they trust and found to be liveable, manageable and efficient. Thus, they develop systems of self-management and healing,

suitable for their beliefs, values and personal priorities. These perspectives provide insights into the potential role of alternative and traditional medicine as important resources in public health practice for diabetes care. It was also well-noted that the use of alternative and traditional medicine was mainly as complementary medicine. Many of the users also desired integration of most of these complimentary services within the mainstream, health system in the UK for easy access. However, it should be noted that additional research into this area of study is still needed to have an elaborated knowledge about the use of traditional and alternative medicine and the role it plays in the treatment and management of diabetes. In addition, people's cultural values and goals need to be taken into consideration when doing studies that are behavioural and health-related, for improved health practices. This can help in developing effective, practical and personal strategies for promoting the health and wellbeing of people with T2D and some other disease prevention. However, this could employ an interdisciplinary approach to health promotion guided by a shared vision of a healthy environment and a sustainable community. Also, HCPs should be encouraged to understand better the potentials of traditional and alternative therapies. It can also provide people with the opportunity to have a full range or combined health care services that can contribute to reducing health inequalities and improving people's well-being.

Furthermore, the research has uncovered some silent voices that were never heard among BsSA communities and HCPs (6.3.4). This indicates that the dominant views usually observed and presented in the BsSA communities and among HCPs regarding culture and diabetes self-management behaviours do not completely reflect the realities and consensus in diabetes intervention. Additionally, the research has shown that there is a lack of cultural skills and initiatives for diabetes intervention among BsSA communities as interventions remain clinically and medically driven. This has not helped to empower HCPs with the

necessary cultural skills to provide adequate diabetes care for these communities. This could also be due to the lack of targeted resources to run such culturally tailored programmes.

Analysis of the study findings was informed by the PEN-3 public health cultural model, which moves beyond individualistic and bio-medical explanations of diabetes. This theory posits a multifaceted causal model in which cultural beliefs and identity operate in recognised illness experience, outcome expectations, and perceived facilitators in self-management behaviours and well-being. The study findings present the interface between these behaviours and health-seeking practices. Cultural beliefs were found to be of paramount importance in self-management of diabetes. Culturally appropriate advice and services from healthcare providers and the significance of narratives of people in managing diabetes are particularly critical for informing ways of optimising healthcare services among BsSA communities are critical. A broad interpretation of individuals' narratives of diabetes, their social and cultural context and their relationships with health care providers contributes to the debate about power relations between providers and users of healthcare. People's beliefs and experiences in their collective ability to achieve behavioural change play a fundamental role in policy and public health perspectives to health promotion and disease prevention.

7.3. Concluding statement

Overall, this study is informed by contemporary perspectives on cultural beliefs that presents the views of people living with T2D within the context of health behaviours and lay belief system. The study identifies the tension between the mainstream representation of diabetes within the medical framework and the Black African lay belief support system. This study shows that the public health representation of diabetes solely within a medical framework is not being heard because of the lay belief system and that the lay beliefs of people living with

T2D are not utilised because it is not recognised within the mainstream health system. However, the findings from the study revealed that both systems could benefit from each other. Cultural knowledge and its interpretation within a community cohesion offer an understanding of the lived experience of T2D that can potentially promote a more holistic approach to healthcare management that could provide better health outcomes and behaviour change. Understanding the root causes of the prevalence of T2D amongst Black African populations, through listening to them, articulating their understanding of health, and their experience of living with and managing their diabetes can help create more culturally tailored and community-centred intervention programmes and thus potentially enhance self-management and promote community engagement. The use of the sociocultural approach to assess existing diabetes interventions within the medical framework around diabetes policy and practice, therefore, advocates for culturally-tailored and community-centred interventions that would provide a better understanding of individual's health needs to improve health outcomes.

This study moved from an individualistic and medicalised approach to treatment and management of diabetes to a collective perspective, which considers the broader social and cultural perspectives, and lived experiences underpinning self-management behaviours among the BsSA communities. This approach draws upon the disciplines of public health, sociology and anthropology. The interdisciplinary-nature of the study allows the exploration of the sociological perspective of diabetes self-management through understanding the community lay belief system to address the wider determinants of the social and cultural-related health problems and needs, which looks beyond the medically oriented knowledge about diabetes. Recognising the lay belief system allows an opened opportunity for non-medical explanation of diabetes-related experiences. As social and cultural factors have a

considerable impact on the health behaviours of individuals and communities, responses to care and management should be strategic and recognise that public health and diabetes policies require a social-cultural agenda for improved health outcomes.

As previously discussed in this thesis, this study has reaffirmed that social-cultural dimensions of health need to be addressed in a collective approach to reveal the complexity and uniqueness of individual and community interactions, which weave together to influence self-management and health-seeking behaviours. An individualistic approach would not have allowed the broader insight into the interconnectedness of culture and health beliefs, and the relationship with the behavioural transition. This research offers the opportunity to consider anthropological and sociological based recommendation to health care providers and policymakers to work effectively with culturally engrained communities.

Effective management of T2D among the BsSA communities calls for a collaborative intervention at the local level with community networks like churches, mosques, African organisations and African stores. A collaborative effort is needed to increase the awareness of T2D and the clear explanation of the reality of the role of cultural and health beliefs on self-management behaviours. This approach is essential at local, national and international levels if we are to control the growing prevalence of T2D among BME communities. Further exploration of the relationship between diabetes self-management behaviours, health-seeking practices and community networks is needed to validate the significance of the PEN-3 public health cultural model. On the wider scale, intervention using the PEN-3 public health cultural model in the management of diabetes can be adapted for controlling and preventing diabetes-related complications; thereby promoting health equalities benefitting the individual with T2D, the communities and the society.

While the need for the culturally tailored programmes and culturally skilled HCPs has been identified in this study, there is a need for an on-going engagement with HCPs to understand their perspectives and willingness to deliver the service that would require them to upgrade their cultural knowledge and skills. It could be argued that in order to achieve an effective impact of diabetes care, at both individual and population level, a collaboration between HCPs and local communities should be considered as a major priority and actioned within the policy framework that would improve the health outcomes of the BsSA communities. This will help to reflect the needs and concerns of both the service provider and service users underpinned by local policies and strategies. Understanding their perspective would help higher management authorities to understand sustainable ways of providing adequate and effective diabetes care. Thus, this could lead to the development of the new initiatives based on the evidence and views of people living with T2D and their HCPs, rather than being solely based on the decision of policymakers and the medical representation of diabetes management.

7.4. Recommendations for future research

This study provides a conceptual framework for the better understanding of the role of culture and health beliefs among BsSA communities. However, based on the rationale and findings from this study, the following are recommendations for future research:

7.4.1. Broadening the use of ethnographic approaches in diabetes study to identify wider determinants of health

This study recognised the importance of ethnographic approaches for detailed narratives of diabetes-related beliefs and behaviours among the BsSA communities. Ethnography as a cultural subset of anthropology serves as a technique for considering “*the instructive power of less visible or less quantifiable details from such smaller, yet still instructive samples*” (Smith Morris et al., 2012. p. 3). This approach also allowed BsSA communities and the researcher to construct a platform that could positively foster further engagement and inclusion in the implementation of diabetes prevention initiatives responsive to the community needs (Wallerstein et al., 2011). Acknowledging the value of ethnographic methods and perspectives for understanding the complex and dynamic nature of diabetes interventions in communities is significant for improved health outcomes. This approach to diabetes study could also help HCPs to further identify other hidden barriers to effective self-management and identify wider determinants of health. Acknowledging the voice and views of this group through their lived experiences and environment has the potential for promoting the understanding of the issues faced by the community and the empowerment that could potentially enhance positive behavioural changes in the communities. This could provide a way of enabling services that are engaging and could inform behavioural health interventions that would allow individuals to take responsibility for their diabetes self-management.

The issues of silences among BsSAs living with T2D who feel their knowledge is not being valued because of an existing structured health system that is based on the medical model, and the HCPs who are silenced about making the changes because of existing policies and professional knowledge (see 6.3.4), could also be further explored using the ethnographic

approach. This would help in identifying the other factors contributing to the gaps between lay and expert knowledge and the impact of health behaviours.

7.4.2. Increasing diabetes knowledge and awareness among the BsSA communities

It was found that the level of knowledge and awareness among participants about diabetes were insufficient to improve health behaviours. Specifically, the HCPs interviewed during this study agreed that changes and transition in nutrition and lifestyles, particularly among the African communities, have been contributing to the increase in T2D. HCPs need to understand the cultural behaviours associated with eating traditional food and dietary patterns rather than simply advocating a supposedly ideal diet based on the medical model. They also need to reduce the use of medical terminologies to ensure a clear understanding of treatment regimens.

Diabetes policies and programmes should recognise the lived experiences of PLWD beyond their diagnosis. Interventions should be more person-centred rather than being patient-centred. The social construction of diabetes needs to be considered in all policies and programmes targeting diabetes and high-risk communities. This recommendation can be applied to other health issues and healthcare settings.

7.4.3. Improving cultural-competency for HCPs

Culturally-competency training should be provided to HCPs in order to support the development and implementation of specific community-based and culturally tailored interventions and to create effective diabetes awareness in the BsSA communities. This will help those that are newly diagnosed to come to terms with their condition and facilitate their

navigations and transition through the various services available to them through their community networks. This study calls for health promotion and health education beyond people attending medical care facilities to promote earlier care-seeking and adherence to recommended diabetes care and management. HCPs need to be consistent with diabetes cultural knowledge and traditional and alternative practices for better management of diabetes. The mainstream health system should embrace the importance of collaboration with health practices that are culturally embedded in their response to disease treatment and management. However, before embarking on capacity-building and the empowerment of cultural skills for HCPs, it is necessary to determine the nature of the knowledge and skills that these HCPs require to deliver adequate care and services efficiently.

7.4.4. Involvements of community networks in diabetes intervention through health promotion

Community mobilisation and engagement has proven to be more effective in addressing health issues and reducing health inequalities rather than just focusing on improving health care services and adherence to treatments. This should, therefore, be prioritised as one of the major strategies for improving health and self-management behaviours. The policymakers need to take responsibility for promoting the widespread involvement of community networks as a strategy to enhance efficient care delivery both at a national and local level for people living with T2D. This study shows that religious beliefs, use of traditional and alternative medicine, consumption and preferences of traditional African food and other cultural values play significant roles in self-management and health-seeking behaviours. An effort is therefore required to engage with community gatekeepers and HCPs outside the mainstream to improve care services provided to people living with T2D among the BsSA communities. However, this community participation in the intervention process should not

merely be the mobilisation of people or community gatekeepers to accept the intervention provided to them. Rather, a shift from health education, which involves just providing knowledge, for health promotion; involving changes in self-management behaviours and attitudes, and recognition of community empowerment. Thus, through health promotion, communities are able to take control of their own health and beliefs, which allows for self-reliance and empowerment which is a key element of comprehensive primary health care. Community mobilisation and culturally-appropriate empowerment of ethnic minority groups have been shown to substantially improve self-management behaviours and health outcomes (Attridge et al., 2014, South, 2015). Adopting this model will contribute to reducing the burden of T2D among the BsSA communities and reducing the burden of the disease as a significant public health issue in the country

The current diabetes intervention strategies for developing local 'assets' to support and engage with people from the BME community focus on growing self-help groups. Although there is evidence from another study that the promotion of self-help groups within the BME communities are effective for PLWD, these platforms are not being widely accessed (Bashir et al., 2016). The involvement of communities has been mainly passive to date as the community only responds to professional direction and advice. This study shows that there are a range of other community networks and assets (such as churches, mosques, community groups and organisations, African stores) that could be utilised more effectively, if they are being empowered with the right skills and information, to promote active involvement and participation in health intervention programmes and uptake of diabetes care and services. Recognising the relevance of culture through community networks could facilitate the contribution of multi-dimensional perspectives on diabetes-related health and behavioural

challenges faced by BsSA communities. Involving communities in their health through the recognition of their culture and beliefs can greatly help in improving their health outcome.

Concluding points for future research

- Investigate the effectiveness of community-led health information networks, including health promotion centres associated with ethnic minority populations' religious-cultural beliefs. This would create possibilities for both the person living with T2D and their community networks to have a shared understanding of the responsibilities involved in effective diabetes prevention and management.
- Qualitatively explore HCPs perceptions and understanding of BsSA eating patterns and how these might guide the diet regimens given to people living with T2D. This approach might clarify the perceptions about Black African traditional foods and establish if HCPs hold stereotypical views about these communities.
- Consider a mixed method approach to further investigate the phenomenon of silence voices and disempowerment on cultural issues among PLWD and HCPs.
- In addition, the findings on the use of traditional and alternative medicines for the treatment and management of T2D among BsSA communities suggest a further study to explore and evaluate the opportunities for and impact of integrating traditional and alternative services; including those already offered by the medical care system to improve the general care and management of diabetes. This assessment will help to maximise the benefits of alternative therapies that could be of great value to the health needs of the people living with T2D and improve the provision of quality care in the community within a primary care setting. This will also help to recognise the areas of poor health outcomes that need improvement. Real improvements in diabetes care and outcomes among BsSA communities require active engagement and collaboration

with local community networks that provide these alternative treatments. This could contribute significantly to the aims of tackling health inequality and promoting health at the local level.

7.5. General reflection on the doctoral research process

It is imperative that I reflect on my personal experiences, contributions, benefits and challenges in this study as part of a learning experience for future research. Therefore, I would like to reflect on this whole study based on the stages stated by Bond (1988). These stages of reflection are shown in the figure below and discussed afterwards.

Preparation of research ⇨ Engagement with research ⇨ Processing of research

Preparation

I chose this research title to study because of my interest in the significance of culture on disease management and promoting health among the BME communities. I also had more interest in people living with T2D and exploring possible ways of improving the healthcare services provided to improve health outcomes. This was follow-up research from my master's dissertation, which was on the use of complementary and alternative medicine (CAM) in the treatment of diabetes, looking at the perspectives of PLWD and CAM practitioners. The impetus for undertaking further research was embedded in the experience with community health intervention programmes with the BME communities living with T2D, whereby the strategies and activities being implemented was seen as being medicalised and professionally focused on its administration. This was particularly evident in the low attendance and engagement of the BsSA population, as compared with other minority ethnic

groups. Therefore, this study aimed to explore the cultural factors that could enable positive self-management and health-seeking behaviours among the base communities.

By wanting to recognise the complexity of self-management behaviours among the BsSA communities, the researcher, sharing the same cultural identity with the study participants with T2D was beneficial for the study. I was able to use my African identity and cultural skills in negotiating access into the communities and researching on a topic seen as a major public health issue. Moreover, I realised that the research participants saw themselves as contributing to their communities by discussing diabetes self-management based on their lay belief system, lived experiences and cultural values. Overall, this impacted positively on the research process, especially at the data collection stage where the researcher was able to easily engage with participants who were more open to sharing their views and experiences with diabetes services provision during interviews. This could also, be attributed to the effective communication skills of the researcher in both local and professional languages (both as an insider and outsider researcher, see 4.3.3.3 and 4.3.3.3). It was also helpful to be perceived as being approachable and being a good listener.

Furthermore, my active involvement in health promotion and intervention programmes within these communities created an accessible pathway for sharing the importance of the study to these communities. However, it is important to mention that I also experienced opposition and lack of enthusiasm for the study from some of the research participants. These participants were concerned about researchers and professionals approaching communities only to gather information, without meeting their community needs. These concerns were potentially mentioned because I was viewed as a professional and working for the benefit of health system establishment at the expense of the BsSA communities.

Reflecting on the recruitment of participants through the NHS, there were issues arising the lengthy process of ethical approval for the research and the identification of participants living with T2D being characterised as patients. In the reality of the study, which focuses on the broader discussion of non-medicalisation of diabetes, it was, therefore, considered to recruit participants through the community channels, such as voluntary organisations, self-help and support groups, religious centres and community organisations. These identified issues were discussed with my supervisors, and it was understandably considered that the study should focus on recruiting participants through identifying community channels within the local communities that the researcher already had access to for the study and a broader scope of the study. As a result, the researcher focuses only on recruiting participants through voluntary and community organisations, self-help and support groups, and religious centres.

This study affirms the value of social-cultural study as part of public health, health promotion theories and diabetes policy. The in-depth and comprehensive way in which the data has been collected and described in the study is distinctive in its contribution. The qualitative and ethnographic approach of this study, as opposed to the mostly quantitative findings on diabetes in previous studies, provides insight into an individual's lay belief system by moving past the 'what' and 'do' questions into the 'how' and 'why' lives and beliefs are being shaped by collective cultural and self-management choices among the BsSA communities. The sociological perspectives of this study have revealed the understated changes in cultural transition and behavioural patterns and enabled the development of knowledge that will enhance public health policy, by addressing the wider determinants of diabetes-related behaviours. It has allowed the researcher to identify and shed light on the broader awareness of understated and intersectional drivers that collectively influence self-management

behaviours among the BsSA communities. Thus, the study findings add importance to the need for a more holistic approach, emphasising that diabetes intervention is beyond the provision of treatment and medical information. It requires community engagement and addressing the wider determinants of health for better health outcomes.

Engagement with the research

The research process was engaging for me. Although it was not an easy task as it involves searching the internet, books, journals and articles for secondary data that are relevant to my research topic and that would be useful for the study, I was able to design a Gantt chart (see Appendix L) to help me plan my work for the whole research. Though there were times where the plan was not strictly followed due to some changes or delays, it served as a tool to guide the research within the required period of the study. Although I still found it challenging to access the HCPs and policymakers due to their busy schedules, the sampling method used for the study assisted in minimising the challenges. The interviews generally went well, through analysing the data was another demanding stage of the research, as it requires the transcribing of data and detailed analysis of the information gathered for the study. Acquiring skills for data analysis with the use of software such as Nvivo helped to concise the information effectively. I must concede that I gained a lot of skills in using it for navigating through the research process.

Processing of the research experience

This research process thought me to be more confident, well-organised and time-conscious. The confidence and experiences that I have gained during this study have also enabled me to write two papers focusing on sensitive health issues within the BsSA communities. Both papers have been accepted for publication. I have also learnt some useful skills from the

ethnographic approaches in this study that should be beneficial to me for future research. Learning the methods of analysing qualitative data in research through the use of Nvivo was an added advantage to my field of knowledge. I can confidently say that the whole study was a positive learning experience for me.

It is also important to mention that despite my endeavour to stay neutral on the culturally contested issues as a researcher who shares the participants' cultural identity, the position was sometimes hard to maintain. It is therefore important that the researcher's emotions, feelings and beliefs be openly acknowledged when the researcher share identity with the community being studied. Discussion with my supervisors was invaluable in navigating some of these personal and professionally challenging periods. The research process has allowed me to want to pursue further studies and explore postdoctoral opportunities.

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APPENDIX

Appendix A: Project Approval

NOTTINGHAM
TRENT UNIVERSITY

Damilola Oyewole
Apartment 2 Brook Court
Player Street
Nottingham
NG7 5PP

Imogen Edwards
Graduate School Administrator
Nottingham Trent University Graduate School
Tel: +44 (0)115 848 8124
Fax: +44 (0)115 848 8700
Email: imogen.edwards@ntu.ac.uk

20 February 2015

Dear Damilola,

Application for Project Approval for a Research Degree

I am writing to confirm formally that your research proposal has been accepted by Chair's Action on behalf of the College Research Degrees Committee. Your research project has been registered for Mphil with possibility of transfer to PhD.

The title of your project is 'Cultural and health beliefs as a causative factor for diabetes management: Black-African community in the UK'. Your supervisory team comprises Dr Linda Gibson as your Director of Studies, plus Dr Graham Bowpitt and Mrs Ann McCarthy. If any of these details change in the future, please could you notify me at once, as we are required to keep the College Research Records up to date.

The date of your registration is 07 April 2014. You will be expected to transfer from MPhil to PhD when sufficient progress provides evidence that the development to PhD has been made. **This should happen after 12 months but no later than 24 months from your registration date.** Please refer to regulation part J for further guidance. Please note that candidates who wish to transfer to PhD should apply on form RD2T.

Yours sincerely



Imogen Edwards
Graduate School Administrator

cc: Dr Linda Gibson

Nottingham Trent University
Burton Street, Nottingham NG1 4BU
Tel. +44 (0)115 941 8418

Appendix B: Research and Ethics committee approval

NOTTINGHAM
TRENT UNIVERSITY

Damilola Oyewole
Postgraduate Researcher
School of Social Sciences
Nottingham Trent University
50 Shakespeare Street
Nottingham
NG1 4FQ

Anton Muszanskyj, MA PG Cert
Research Governance and REF Manager
Research Office
Nottingham Trent University
Arkwright B113
50 Shakespeare Street
Nottingham, NG1 4FQ
Email: anton.muszanskyj@ntu.ac.uk
Telephone: +44 0115 848 8117

22 February 2018

Dear Damilola

Application to the College Research Ethics Committee

Please accept this letter as written confirmation that your application (No. 2015/33), entitled: *Cultural and health beliefs as causative factors for diabetes self-management amongst Black-African community in the UK* was considered by the College's Research Ethics Committee (CREC) and approved on 29 May 2015.

Yours sincerely



Mr Anton Muszanskyj
Research Governance and REF Manager
Research Office
Nottingham Trent University

Appendix C: Consent form

Participant ID.....



*Sociology Division
School of Social Science
Nottingham Trent University
50 Shakespeare St,
Nottingham, NG1 4FQ*

Informed Consent Form

Purpose:

The purpose of the research is to explore and gain an insightful knowledge of the role and impact of culture and health beliefs on diabetes self-management and treatment among people living with type 2 diabetes in Black African communities. It also explores how statutory, non-government bodies and support organizations understood and relate to these impacts, what kind of support is offered and the nature of local multi-agency working in relation to providing effective support for the people living with Type 2 diabetes.

Procedure:

You are being asked to participate in a semi-structured interview lasting approximately 1 hour. The interview will consist of a number of questions about your awareness of people's culture and health beliefs on diabetes management and experiences of working with Black African individuals living with type 2 diabetes. The interview will be recorded on a digital voice recorder with your consent. Please tell the interviewer if you do not wish to answer any of the questions put to you.

Voluntary nature of the research/Confidentiality:

Your participation in this research is entirely voluntary and you may refuse to answer any of the questions or terminate the interview at any point. You are reminded that you have the right to withdraw your participation before the interview date and also the research data within 6 weeks of the completion of this interview session. Your name and personal information will not be connected to your responses. Information that would make it possible to identify you will not be included in the report. Your participant ID will only identify your input. The data will be accessible only to those working on the project (the principal researcher and supervisors). Your data will be kept securely and appropriately stored as encrypted files.

Statement of Consent:

I have read the information above and I understand the purpose of the research and my part in it. I have asked any questions I had regarding the interview procedure or research and they have been answered to my satisfaction. I understand that I have the right to withdraw my data at any point during the interview or within 6 weeks of completing this session by contacting the principal researcher stating your participant ID. I consent to participate in this study.

Name of principal researcher_____Damilola. A. Oyewole_____

Date: _____

Signature of Participant_____

Thank you for your participation!

Appendix D: Participants information sheet for interview

Participant's ID.....



*Sociology Division
School of Social Sciences
Nottingham Trent University
50 Shakespeare St,
Nottingham NG1 4FQ*

Participant Information Form

TITLE OF RESEARCH: The Role of cultural values and health beliefs on diabetes self-management amongst Black-African community in Nottingham.

Thank you for agreeing to consider participating in this research project. Before deciding whether to grant me an interview, I feel it is important that you understand the reason why the research is being conducted, and what your participation will involve. I would be grateful if you would take the time to read the following information carefully and discuss with your colleagues or other people if you wish. Please do not hesitate to contact me if any of the information is unclear or you wish to discuss your participation in this project.

What is the purpose of the study?

This study is primarily concerned with gaining an understanding of the cultural and health beliefs about Type 2 diabetes causes, management and treatment among the Black African community in Nottingham and how these beliefs along with their cultural experiences impact their health and self-management behaviour and engagement with service care. Also, the study will be comparing the perspectives of the people living with diabetes with the language from health professional and policymakers. This will be identifying how the stakeholders understand diabetes management locally and analysing the different discourses used to understand diabetes self-management among the Black African community.

I will be conducting semi-structured interviews with Black African people living with diabetes and several statutory and third sector agencies. The study has been designed in order to gain an understanding of how often individuals from these agencies conceptualise culture and health beliefs and the impacts on the social, behavioural and economic position of people living with diabetes and other health outcomes.

The acceptability of the effectiveness of social-cultural factors in healthcare management can help provide support for people living with type 2 diabetes, engagement with intervention programmes and reducing health inequality.

Who is running the study?

The project is being conducted by Postgraduate research student Damilola Oyewole and supervised by academics from the Sociology Division of the School of Social Science at Nottingham Trent University for research conduct.

Why have I been chosen to take part?

You have been selected for interviewing as I believe your experiences with diabetes, people living with diabetes and expertise in decision making in this field will be invaluable to my research. I believe it is important to understand the issue of culture and health beliefs in diabetes self-management from a number of different lay and professional perspectives to gain a better understanding of the issue and the effectiveness of multi-agency partnerships.

Do I have to take part?

Your participation is entirely voluntary in this research. You are free to participate, and you may decline to answer any of the questions if you so wish. Furthermore, you can withdraw from the study at any point without any negative consequences, either by contacting me before the interview, asking to terminate the interview, or withdrawing your data after the interview has taken place.

If you do decide to take part, I ask that you read and fully understand the information on this sheet, and you will also be asked to complete and sign a separate informed consent form.

If you decide not to take part in the research, you will not be asked to give any explanation or reasons for your withdrawal.

What do I need to do?

I would like you to take part in an interview lasting approximately 1 hour in any location and arranged time that is convenient for you. Interviews will be taking place within 10 months, and I will contact you to arrange a date and time that is convenient for you. The interview will be carried out by the researcher, following a pre-set schedule and will follow a semi-structured format. Follow up interviews might be required as the study continues until the end of the research. As part of the informed consent form, I would like your permission to record the interview with a digital voice recorder to ensure the data you provide is accurately documented.

What questions will be asked in the interview?

A full copy of the questions that are going to be asked in the interview will be provided in advance, and you will have the chance to read through them. Any questions that you would not feel comfortable answering will be omitted from the interview. If you are unsure about any of the questions, you may contact the researcher to discuss them further before the interview.

In addition to this, if you feel uncomfortable whilst in the interview you may refuse to answer, or give no comment to any of the questions, and the researcher will continue with the following question.

What will happen to the information I provide in my interview?

The audio recording of your interview will be transcribed and analysed by the principal researcher and information will then be incorporated into the findings and conclusions of the research. Although data collected from the interview will be used in the writing of the research, your name will remain completely anonymous as any details or any information that identifies you or your organisation, or that gives any clues to your identity, will be changed in the transcripts so that your identity remains concealed, and any other thing that could identify you will be removed. You will not be asked to provide any further personal information apart from your age, gender, ethnicity, marital status and your religion (people living with diabetes). No name or any other information about your group or organisation will be required of you beyond what is being asked during the interview that could identify you or your organisation. The information provided and participants' inputs will only be identified by participant ID number. All transcripts will be kept on a private secured laptop, in encrypted and coded files. The laptop and transcripts will be kept in a locked drawer in a secured office to ensure your data's security.

During and after the study, all transcripts will be kept securely for a period of five years, after which the un-anonymous data will be destroyed in a secure manner.

At the end of the study, all the transcripts will be deposited in the archive of research material maintained by the Economic and Social Research Council. This is usual practice because it makes valuable research data available to other researchers. However, the transcripts will be fully and completely anonymised before they are archived. We are confident that these precautions will ensure that no-one will be able to trace the transcript back to you or your organisation.

How will the research team protect my confidentiality and anonymity?

Your response and contributions are considered completely confidential. Therefore, all information and transcripts provided will be fully anonymised in line with the data protection principles and treated confidential and will be kept in a secured location always during and after the study. Although certain University assessors, government reviewers and investigators may need to see the study reports and recordings to make sure research is carried out in the most appropriate way, you will remain completely anonymous all through the study. Pseudonyms will be used during write up so your original name cannot be identified and the voice recording will be destroyed after the information has been transcribed, analysed and examined.

Hard copies of data will be kept in a locked drawer, and electronic copies will be stored on a private computer in encrypted and password protected files in line with the British Sociology Association's code of ethics.

You will not be named or otherwise identified in any publication arising from this research unless your role forms part of a narrative that is already in the public domain (for example, if you were the named author of a published document or gave evidence to a public inquiry relevant to the study). No unpublished opinions or information will be attributed to you, either by name or position. The location of the research will also be anonymised.

The research team will exercise all possible care to ensure that you and the organisation you work for cannot be identified in the write-up of findings.

What are the possible risks/disadvantages of taking part?

The main cost to you will be the time taken to the interview as there is no known or anticipated risk to you as a participant in this study. However, if you feel tired during the interview, the interview will be stopped and resumed at a later time or reschedule for another day. The risks to you may include providing information that you may not feel comfortable with. However, as outlined above, any information you do provide will be kept anonymous and secure and will not be shared with anyone outside the research team. In addition, you can choose not to answer any of the questions or withdraw your data at any time until the final date specified for withdrawal of data.

What are the possible benefits/advantages?

I hope that you will find the interview interesting, and will take satisfaction from helping to develop a greater understanding of people's culture and health beliefs in diabetes self-management. I also hope that you will find the results interesting and helpful to provide sustainable health support for people living with Type 2 Diabetes. The results of the study can be made available to you as a report, upon request, when the research is completed.

What will happen to the results of the research?

The research team will write up the results in a report and hope to have them published as academic articles or in academic publications. We will also publish a report of our results which may be read by practitioners, senior police officers, academics, students and others working within the field of Public Health and Diabetes management.

How can I find out more about this project and its results?

For more information about the project, please do not hesitate to contact me, or one of the research team. I will send you a full copy of the interview questions before the interview and an electronic copy of the report once the research is completed.

Has the study been reviewed by anyone?

The research has been subject to ethical approval by the University's College Research Ethics Committee. It has been designed with reference to the British Criminological Society's code of ethics.

Who is responsible for the study?

The academic supervisors on the research team will be responsible for the conduct of this research.

Contacts and further information

Please, if you have any concern or require further information on the study, feel free to contact any member of the project team below on the following email address or phone numbers.

Dr Linda Gibson
linda.gibson@ntu.ac.uk
Tel: 0115 848 5593

Dr Graham Bowpitt
graham.bowpitt@ntu.ac.uk
Tel: 0115 8485610

Ann McCarthy
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Tel: 0115 8485645

Damilola Oyewole
damilola.oyewole2010@my.ntu.ac.uk
07405841571/ 07456507410

Or at the following address:
C/o Dr Linda Gibson
Social Work and Health
School of Social Sciences
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Nottingham
NG1 4FQ

Acknowledgement- Thank you for agreeing to participate in the study. Your response and help during the study are greatly appreciated in the completion of my doctorate degree.

Appendix E: Sample of flyer for interview

What do you think about Diabetes Self-management and Cultural Beliefs?

have your say

You are a Black African with type 2 diabetes

Your experiences and views will be valuable for policy making on diabetes management

Impacts of Cultural beliefs and influences on diabetes self-management

Face-to-face interview. No right or wrong answer. My thoughts and experiences matter for the study

Your participation is entirely voluntary. You can withdraw my information from the study

NTU Independent researcher will be doing the interview

Reports from findings to be disseminated to NTU, Nottingham City Council

Your name and identity will remain anonymous as confidentiality will be maintained

Your responses are appreciated and you can have a copy of any publication arising from the study

Independent researcher can be contacted on 07456507410 or damilola.oyewole@my.ntu.ac.uk

Diabetes management and cultural beliefs

WHAT DO YOU THINK?

have your say

What is it about?

Would like to speak to Black Africans with Type 2 diabetes about their experiences and cultural beliefs on diabetes self-management.

What is it for?

Would like to find out the impact of cultural beliefs and influences on diabetes self-management. The acceptability of the effectiveness will provide sustainable support for people with type 2 diabetes, engagement with intervention programmes and reducing health inequalities among Black African population in the UK. A report will be written of what the researcher finds out to the Nottingham Trent University, Diabetes UK and Nottingham City Council.

Why do you want to speak to me?

Would like to speak to you because your experience with type 2 diabetes will be valuable on decision and policy making on diabetes self-management among Black African population in the UK.

Who is doing it?

Independent researcher from Nottingham Trent University will be doing the interview. The researcher is a doctoral researcher from Nottingham Trent University with research interest on diabetes management and Public Health.

What will I be asked to do?

Taking part would involve an interview – not exceeding 45min. We will talk to you about your experience with type 2 diabetes self-management and perceptions on cultural influences among Black African population.

There are no right or wrong answers – interested in what you think and your experiences. If it OKAY with you, we would like to audio record the interview. This is so that we don't have to take notes and don't forget what you tell us.

Do I have to do it?

No, it's up to you. Your participation is entirely voluntary in this project. You don't have to answer any questions you are not happy or comfortable with. You are free to withdraw your information from the study by contacting the researcher.

Will I find out the results?

Your responses and contribution is appreciated and a copy of any publication arising from the research required by you will be highly honoured.

Will anyone see my answer?

Only the principal researcher will have access to the recording of the interview, the transcription and analysis of the findings incorporated into the research. Your name will remain completely anonymous as any detail or information that could identify you will be changed in the transcript so that your confidentiality is maintained.

I want to be part of it, who can I speak to?

Please do contact the researcher on 07456507410 or you can email: damilola.oyewole2010@my.ntu.ac.uk

Appendix F: Interview schedule guide for Black Africans living with type 2 diabetes

Participant ID.....

INTERVIEW SCHEDULE

PEOPLE LIVING WITH TYPE 2 DIABETES INTERVIEW GUIDE

Thank you for agreeing to participate and being interviewed in this research. This interview will last approximately one hour and will be quite informal during the process. Please answer the questions as fully as you can but I will be making sure all discussion remains with the themes of the research. I will be recording our conversation as mentioned in the information sheet, but I can assure you all information will be completely anonymous and will remain secured. Pseudonyms will be used during write up, so your original name cannot be identified, and the voice recorder will be destroyed after information has been transcribed.

This interview is to provide us with an opportunity to understand your broad views and perspectives on the role of cultural values and health beliefs on diabetes self-management among Black African communities. So, I will be interested in easy to understand thoughts and views. I understand you may say things that are unrelated to what we are discussing, don't worry about it as your confidentiality is highly important and as stated in the information sheet, any information provided outside the interview schedule will be removed.

The information generated will be used in the reformation of diabetes policy to improve the delivery of health care services for people living with type 2 diabetes.

SOCIO-DEMOGRAPHIC QUESTIONNAIRE

DEMOGRAPHICS: *To begin, I would like to know a little bit about you.*

BACKGROUND INFORMATION:

Age:

Gender:

Marital Status:

Educational level

Occupation:

How long have you lived in Nottingham?

What is your religion? (Christian, Muslim, other religion)

TYPE 2 DIABETES BELIEFS, OPINIONS, PERCEPTION, KNOWLEDGE, ATTITUDE (STIGMA RELATED ISSUES), MISCONCEPTIONS AND HEALTH SERVICE UTILIZATION.

In these next few questions, I'd like to learn your opinions about type 2 diabetes, health issues, and your thoughts about the role of your cultural experiences and health beliefs in managing type 2 diabetes. Your thoughts about these issues are important to me, and there are no right or wrong answers.

IF YES → *Proceed with the questions*

IF NO → *OK. Thank you again for your time.*

THEME 1: Diabetes history

How long have you had diabetes?

How did you find out you have it? What were the major signs and symptoms of type 2 diabetes that you experienced?

Did you experience more or less of the symptoms before you were diagnosed?

Before you were diagnosed with type 2 diabetes, do you have the feelings you might be suffering from it?

*What triggers you to seek care?
What was the major influence on your decision to seek care?*

How did you react when you were first diagnosed with type 2 diabetes?

THEME 2: Knowledge and understanding of the causes and complications of diabetes

Briefly describe what you know about type 2 diabetes? Causes?

Where did you get the knowledge from?

Families, friends, social media, doctors?

Do you think your diabetes is hereditary?

Do you think lifestyle in the United Kingdom could impact on developing type 2 diabetes?

Environmental factors? Pollution? Diet? Processed food? Medication

What are the complications one is likely to get if he/she is not treated in time or managed properly?

What are the reasons why?

How do you tell if your diabetes is under control?

How will you describe the problem of type 2 diabetes in the Black African community?

What are the reasons for it?

THEME 3: Treatment of diabetes

Do you think type 2 diabetes is treatable or curable? *If yes, how? If no, Why?*

Do you think type 2 diabetes preventable? *If yes, how? If no, why?*

Are you taking medication solely to treat your diabetes? Or just change of lifestyle/diet pattern?

Do you see your doctor often for type 2 diabetes treatment?

How often do you have appointment? Frequently or never?

What are the main treatment prescribed to you by health professional (GP, nurses, health educationist, dietician)?

Medication treatment? Health education?

Do you often attend any diabetes programme? (Juggle, T2ONIC, Dietetic support self-help group)

If yes, how often? If no, why? (location, time, structure)

Do you worry about any advice or treatment given?

Any concern or problem with the treatment and its management?

Do you discuss any issue or constraint you face on treatment and management of your diabetes with your GP?

Was the health professionals' response satisfactory or not? Why?

Have you been diagnosed with any other medical conditions, since you've started treatment?

If so, which ones?

THEME 4: Living with diabetes

Have you changed your lifestyle in any way to manage and improve your type 2 diabetes?

Specific dietary changes, Increased physical activity, other treatment?

Do you think exercising regularly helps you manage your diabetes?

What type of exercise do you do? Is there anything that prevents you from exercising?

Does changing your eating pattern help you to manage your diabetes?

Are you restricted to any particular diet?

Do you get support from families and friends in taking care of your diabetes?

What support?

Advice? Personal support? Financial support? Professional support?

How do you cope with having diabetes? mentally, socially, physically, medically, financially?

Does it affect your life/work? Do you share your experiences with your doctors?

Do you feel confidence to discuss about your illness with anyone?

family member and friends?

THEME 5: Role of your cultural values and beliefs on diabetes management

Does your culture have any influence on the way you manage your diabetes?

Response to treatment and advice

What African foods/traditional meals do you still eat with your diabetes? Why?

Cultural values? Cooking style? Taste? Family commitment

Would you respond well to treatment and management advice given by professional if services incorporate people's cultural values and beliefs?

If no, why not? If yes, why?

THEME 6: Use of other therapies and health practices

Do you know of/believe in any cultural/traditional remedies to help maintain good health or prevent illnesses including diabetes?

Which of the traditional remedies/therapies do you use to manage your diabetes?

What made you use the therapy? How did you get the knowledge?

Benefits? How often do you use them?

Does your doctor or nurse know that you use these remedies? (If any)

Does prayer or religious practice play a role in the treatment and management of your diabetes?

THEME 7: Challenges to treatment service and self-management regimens

What are some of the challenges that you face in seeking care at the health care facilities or attending diabetes programme?

*Finance? limited resources? Access? waiting time? Medicalised system?
Level of information provided?*

What else can be done to assist? Health professionals, policy makers

What are the major constraint that you have in adhering to prescribed treatment or management programme?

***Lack of cultural sensitivity by health professionals? Diet pattern?
Environmental factors? Prescribed drugs and diet?***

What can you share about your experience that would help me to understand the barriers and challenges that Black Africans who are diagnosed with diabetes face?

Is there anything else you would like me to add to the research findings?

Okay, these are all the questions that I have for you. Do you have any questions for me?

Thank you very much for your time and help

Appendix G: Interview schedule guide for health professionals

Participant ID.....

HEALTH PROFESSIONALS INTERVIEW GUIDE

Thank you for agreeing to participate and being interviewed in this research. This interview will last approximately one hour and will be quite informal during the process. Please answer the questions as fully as you can but I will be making sure all discussion remains with the themes of the research. I will be recording our conversation as mentioned in the information sheet but I can assure you all information will be completely anonymous and will remain secured. Pseudonyms will be used during write up so your original name cannot be identified and the voice recorder will be destroyed after information has been transcribed.

BACKGROUND

How long have you been practicing?

What is your current practice?

I will be asking basic questions on the knowledge of diabetes before we go to the main questions.

THEME 1: Knowledge and prevalence of diabetes among Black sub-Saharan African community

What are the causes, signs and symptoms of diabetes? How can diabetes be diagnosed?
Is it preventable?

If yes, how? If no, why?

What do you know about the prevalence of Type 2 diabetes among Black African population?

What do you think are the major factors for prevalence and incidences among Black African population?

Why?

What do you think influences people's decision to seek treatment?

THEME 2: Type 2 diabetes treatment and diabetes self-management

Can you describe to me your experience in managing Black African people living with Type 2 diabetes?

What are the main treatment you prescribe to people living with Type 2 diabetes?

What are the educational programmes you recommend to people living with Type 2 diabetes?

**Underlying ideology of programme: formal or informal
How often you think they attend them?**

In your opinion how well do you think diabetes self-management as an approach is effective?

What are the major benefits to the Black African communities

THEME 3: Health professional's relationships with people with type 2 diabetes

Based on your professional experience, would Black Africans living with diabetes seek care early?

And what would make them do so?

How would you know that people with Type 2 diabetes understand the information provided to them and are coping with their treatment and self-management?

*Is the communication level sufficient?
Do you receive feedbacks*

Some people with diabetes may complain of delayed diagnosis simply because their doctor did not diagnose the problem early, as a result of which they may turn to alternative forms of managing their condition. So, based on your experience, would you say that there is a problem with late diagnosis of people with Type 2 diabetes?

*If YES, what strategies do you use to deal with early diagnosis?
If NO, what is the reason and factors responsible?*

THEME 4: The role of cultural values and health beliefs

What do you know about the culture and health beliefs of people living with Type 2 diabetes? Specifically, the Black African community

What roles do culture and health beliefs play in the way they manage diabetes?

*Reaction to diagnosis? Treatment? Health advice
Any challenge? How do you respond to it?*

Do you think that there is a good level of awareness amongst health professionals of the impact of culture and health beliefs on diabetes self-management?

THEME 5: The use of other therapies and practices

Do you know other forms of alternative practices that people living with diabetes seek for care and treatment?

any similarities and differences with your clinical practice?

Do people living with diabetes tell you about the use of other alternative medicines or therapies?

If yes, how often? If no, why?

Do other health practitioners know of any alternative therapies in the treatment for type 2 diabetes?

THEME 6: Challenges to services offered to the Black African communities

What are the common presenting problems about the service offered to Black Africans living with diabetes?

Treatment, diet regimens, advice?

Considering an individual's culture and beliefs, what can you suggest as ways of improving the service?

Do you think that integrating cultural practices with clinical knowledge can help create more collective treatment and management plans that reflect an individual's cultural and health needs?

How might the UK health policies and system respond to the use of alternative therapies or practices for diabetes management?

What other factors do you think policy makers and decision makers could consider as an effective strategy in delivering an efficient health intervention programme for people living with type 2 diabetes?

Finally, is there anything else you would like to add?

Thank you very much for your time and help

Appendix H: Interview schedule guide for policymakers and decision makers

Participant ID.....

INTERVIEW GUIDE: POLICY MAKERS AND DECISION MAKERS

Thank you for agreeing to be part of this research and being interviewed. This interview will last approximately one hour and will be quite informal. Please, you can answer the questions as thoroughly as you wish. I will be recording our conversation on an audiotape, but I can assure you that this information will remain secure and anonymous. Pseudonyms will be used throughout write up, so you cannot be identified or traced back based on information provided. Tapes will be destroyed at the end the research after supervisors have evaluated the results.

BACKGROUND

What's your professional role and experience in diabetes management (s)? (background and experience - health promotion, policy development, prevention strategies)

THEME 1: Knowledge about the prevalence of type 2 diabetes

1. How would you describe the incidence of diabetes in the UK and the situation among Black Africa community?

*- Public health issue? Cost of treatment? The burden on NHS?
- How do you see this reflected? Society, culture, beliefs, media?*

2. What would you consider as the main issue with the increased incidences of type 2 diabetes among the Black African community

*- Is cultural diet considered to be important? Why?
-is there anything else causing the prevalence?*

THEME 2: What are the available services for treatment and management of diabetes?

3. How would you describe the availability of treatment and management services for people with type 2 diabetes?

*The delivery of service?
Location of services*

4. There have been cases of adverse effect or reaction to some medication and had to be replaced with new medication, what is your opinion about this?

THEME 3: Challenges to diabetes intervention among Black African communities

5. There are different views about people with type 2 diabetes not seeking care early or engaging with treatment, what is your opinion on this?

*Finance, gender, age, marital status?
Cultural stigma? Quality of service? Language barrier/Beliefs? Long waiting time?*

6. Do you feel the Black African community has an understanding of the concept of prevention and management of type 2 diabetes as stated in the NHS framework?

Could that be the reason why people access other sources for treatment?

7. In your opinion and experience do you think impact and importance of culture and health beliefs on diabetes management could have a major influence on the NHS Framework for Diabetes?

*If yes, why? How?
If no, why?*

THEME 4: THE ROLE OF CULTURAL VALUES AND HEALTH BELIEFS

8. Looking specifically at the Black and minority ethnic community, such as Black Africans, do you feel that consideration of people's culture and health beliefs can improve prevention of diabetes, health choices and engagement with services?

Traditional eating pattern and cultural diet

9. Would you say health professionals are conversant enough in the knowledge of people's culture in the management of their diabetes?

If yes, how? If no, why?

What is your opinion about other therapies that people use in the treatment and management of type 2 diabetes?

Are you aware of any benefits of the therapies?

Do you feel the use of other therapies is becoming part of the community because of other challenges with the NHS? Availability/Access

10. In your experience, would you say health professionals and policymakers are conversant about the use of these other health therapies in the treatment and management of type 2 diabetes?

THEME 5: EXISTING DIABETES POLICY

11. Looking now to specific strategies for type 2 diabetes prevention policy, what are your views on current strategies, – what will you consider to be the most / least effective?

- *an integrated approach for non-communicable diseases linked to diet, physical activity and being overweight or obese (addressing risk factors, variation in population)*
- *healthier lifestyle information (physical exercise, healthier food choice and diet, portion size meal and drinks)*
- *Working with community networks*
- *Cultural sensitive programmes*

12. What do you feel are the issues with evidence-based diabetes policy?

E.g. a move towards using the best evidence available from individual's experience rather than scientific certainty for prevention and management.

13. How do you see the role of cultural beliefs on diabetes self-management and prevention policy?

- how can an unstructured perspective of community engagement feed into the policy?*
- could there be any conflict in terms of ideas and opinions?*

14. Which other support system would you consider for improved health outcomes among the BsSA communities?

Thank you for your time. If I have any further questions or need to clarify anything may I get back to you?

Appendix I: Participant demographics

Socio-demographic and diabetes characteristics of participants			
Participants	Black Africans with T2D	HCPs	Policy/Decision Makers
Gender	Number of Participants		
Male	7	3	2
Female	21	7	4
Total	28	10	6
Age			
30-40	4	N/A	N/A
41-60	16	N/A	N/A
61-75	3	N/A	N/A
Over75	1	N/A	N/A
No response was given	2	N/A	N/A
Marital status			
Single	3	N/A	N/A
Married	19	N/A	N/A
Divorced/Separated	4	N/A	N/A
Widowed	2	N/A	N/A
Educational level			
Less than High school	2	N/A	N/A
High school graduate	2	N/A	N/A
College	4	N/A	N/A

Graduate degree	16	N/A	N/A
Above graduate degree	4	N/A	N/A
Religion			
Christian	20	N/A	N/A
Muslim	6	N/A	N/A
Other religion	1	N/A	N/A
No religion	1	N/A	N/A
UK born or migrant			
British born Black African	5	N/A	N/A
British migrant Black African	22	N/A	N/A
Self-management /Treatment status			
Diet control only	2	N/A	N/A
Oral medication	4	N/A	N/A
Insulin-dependent	3	N/A	N/A
Diet, oral medication and other alternative remedies	14	N/A	N/A
Complementary/Alternative remedies only	4	N/A	N/A

Appendix J: Breakdown of participants' sources and mode of interview for the study

Black Africans living with diabetes		
Number of participants	Source	Mode of interview
7	Self-help/support group	Face to face interview/focus group
3	Community centres	Face to face interview
10	Churches	Face to face interview
3	Mosque	Face to face interview
4	Families/friends	Face to face interview
HCPs		
Numbers of participants	Role	Mode of interview
2	Doctor	Face to face interview
1	Doctor	Skype
1	Doctor	Telephone interview
3	Diabetes Nurse	Face to face interview
1	Diabetes Nurse	Telephone
1	Specialist Public Health Dietician	Face to face interview
1	Diabetes/Nutrition Educationist	Skype
Policy/Decision makers		
Number of	Role	Mode of interview

participants		
1	Diabetes UK regional manager	Telephone
1	Community and Engagement manager (Diabetes education programme)	Face to face interview
1	Networks & Policy manager (NCV)	Face to face interview
1	Networks & Policy Officer (AHPN)	Telephone interview
1	Policy manager (Public health Nottingham City council)	Face to face interview
1	Health commissioning manager (NCCG)	Telephone interview

Appendix K: Sample of interview transcribe

How did you find out you have it?

I actually got to know... by fault really. My previous role, I was a general manager in a very large company, and part of their activities was every two years we have a health check. It was at that point that it was identified that I have high blood sugar level, but I was not aware of it at the time. Then, I was referred to my GP, and later they diagnosed that I had type 2 diabetes

Commented [MOU1]: Knowledge about diabetes

What were the major signs and symptoms of type 2 diabetes that you experienced?

No... not at all. I became really shocked when I was diagnosed with a severe eye condition due to diabetes, but I was not aware of that either. It came a bit of a shock when the doctor told me you have diabetes, and I am like are you sure? You know I have lived a healthy life, you know I do a lot of... my eyes checked; the way I got to know I had diabetes was quite a bit of a shock to me at the time. If you have it, you do not know until they tell you. Oh yes, I realise I use to feel a bit faint then or maybe you think you've had too much... oh yes, I do feel a bit tired... you might feel oh well, I'm feeling run down or tired you don't actually think it's this condition that is causing it. There are a lot of people with diabetes that don't know they've got it..... You may be displaying only one of the conditions, you know, maybe you're drinking a lot, or you're going to the toilet a lot. However, you know you have not actually linked that to any health condition or think that you have diabetes.

Commented [MOU2]: Diagnosis was a shock

Did you experience more or less of the symptoms before you were diagnosed?

No, because you know you don't actually...if you've got it you don't know until they tell you, then ...oh yes I realise I use to feel a bit faint then or maybe you think you've had too much ..oh yes I do feel a bit tired...you might feel oh well I'm feeling run down or tired you don't actually think it's this condition that is causing it. There are a lot of people with diabetes that don't know they've got it

Commented [OD2(3): Observe signs and symptoms

Before you were diagnosed with type 2 diabetes, do you have the feelings you might be suffering from it?

Honestly, no one will think they've got it. You know in school or where you are working...doctors come in and they might say to you if you think you are feeling too tired, if you do this then you have diabetes. You may be displaying only one of the conditions, you know may be you're drinking a lot, or you're going to the toilet a lot. But you know you don't actually link that to any health condition or think that you've got diabetes...I think a lot or half of the quantity of oil I would have used to prepare my food. Diabetes should not stop me from eating my traditional meal if I want to

Commented [OD2(4): Misdiagnosis

Although staying healthy is expensive here in the UK, especially if you are on a low income. If you want to eat the best and a healthy diet, you need to have enough money. Again, not everyone can afford to be eating organic food all the time because they are even more expensive

Commented [MOU10]: modification of diet

Commented [MOU11]: affordability of staying on diet plan

Where did you get the knowledge from?

A very good friend of mine is a GP, and I call him quite a lot, and I asked him loads of questions and because He [is], not my GP, so he is more open. He tells me this is not what they actually meant; this is what they are actually trying to say x, y and z. so I'm getting the truth because I've got a friend who is a GP as opposed my visiting my GP and telling them the truth. Yeah, I got a lot of inside information from friends... the internet and I read a lot. It wasn't like that 20-30 years ago, not everyone has access to the internet. Now everyone has access to the internet, and you could know as much as your GP. You know what I found out some time ago... the doctors are actually on the internet giving you your diagnosis or getting information about your medication. GPs are just human beings like yourself, and you can get information from the same source. You can inform yourself a lot from the internet.

Commented [MOU12]: got knowledge from friends

Commented [MOU13]: personal responsibility to look after health

Absolutely. Your GP is got 5-10min, they can't tell you all you need to know at that time. So you've got to join groups, join the internet, speak to people that has got diabetes themselves and ask them how they have being able to manage their diabetes. You'll find out there are lot of people that have the knowledge that you can tap into

Do you think your diabetes is hereditary?

Yeah, genetic... but the bottom line is the lifestyle. Whether or not [sic], you will gonna get diabetes because your great grandfather had it, my question is... because if you look back in history how our parents lived a healthy life. They did not drive that time; they walk plenty mile to go to work and walk plenty miles back, they work had in the field... The sugar in their system believe me is drained out and at the end of the day, they have worked really hard. Now our lifestyle has changed significantly with the likes of computers and technology, fast foods... We sit down a lot. Whereas our parent to work a lot and exercise through activities, but we exercise going to the gym. So, things have changed, and we need to recognise it. We have moved from our traditional food; we now eat pasta; many of our parents did not eat pasta. We eat sweet potatoes, now our intake of food is entirely different

Commented [MOU14]: Genetic, lifestyle, hereditary

Appendix L: Screenshot of QSR Nvivo 11

The screenshot displays the Nvivo 11 interface for a project named 'dammy project 1.nvpx.nvp - Nvivo Pro'. The top menu includes FILE, HOME, CREATE, DATA, ANALYZE, QUERY, EXPLORE, LAYOUT, and VIEW. The 'Sources' pane on the left shows a tree view with 'Interviews with BALWD' selected. The main table lists nodes with columns for Name, Nodes, References, Created On, Created By, Modified On, and Modified By. The text view below the table shows the content of a selected node, including questions and answers about diabetes symptoms and experiences.

Name	Nodes	References	Created On	Created By	Modified On	Modified By
BALWD#1	32	34	20/02/2018 10:05	DA	20/02/2018 19:05	DA
BALWD#12	36	39	19/02/2018 17:14	DA	19/02/2018 17:15	DA
BALWD#13	25	26	19/02/2018 17:15	DA	19/02/2018 17:15	DA
BALWD#2	44	48	19/02/2018 17:13	DA	19/02/2018 17:13	DA
BALWD#24	38	40	19/02/2018 17:15	DA	19/02/2018 17:15	DA
BALWD#3	26	27	19/02/2018 17:13	DA	20/02/2018 13:31	DA
BALWD#4	23	24	20/02/2018 15:09	DA	20/02/2018 16:38	DA
BALWD#5	28	28	20/02/2018 16:54	DA	20/02/2018 16:54	DA
BALWD#6	22	24	20/02/2018 17:34	DA	20/02/2018 17:34	DA
BALWD#8	46	52	19/02/2018 17:14	DA	19/02/2018 17:14	DA

What were the major signs and symptoms of type 2 diabetes that you experienced?

No... not at all. I became really shocked when I was diagnosed with a severe eye condition due to diabetes, but I was not aware of that either. It came a bit of a shock when the doctor told me you have diabetes, and I am like are you sure? You know I have lived a healthy life, you know I do a lot of... my eyes checked, the way I got to know I had diabetes was quite a bit of a shock to me at the time. If you have it, you do not know until they tell you. Oh yes, I realise I use to feel a bit faint then or maybe you think you've had too much... oh yes, I do feel a bit tired... you might feel oh well, I'm feeling run down or tired you don't actually think it's this condition that is causing it. There are a lot of people with diabetes that don't know they've got it.... You may be displaying only one of the conditions, you know, maybe you're drinking a lot, or you're going to the toilet a lot. However, you know you have not actually linked that to any health condition or think that you have diabetes.

Did you experience more or less of the symptoms before you were diagnosed?

No, because you know you don't actually...if you've got it you don't know until they tell you, then... oh yes I realise I use to feel a bit faint then or maybe you think you've had too much... oh yes I do feel a bit tired... you might feel oh well I'm feeling run down or tired you don't actually think it's this condition that is causing it. There are a lot of people with diabetes that don't know they've got it.

Before you were diagnosed with type 2 diabetes, do you have the feelings you might be suffering from it?

Honestly, no one will think they've got it. You know in school or where you are working... doctors come in and they might say to you if you think you are feeling too tired, if you do this then you have diabetes. You may be displaying only one of the conditions you

The screenshot displays the Nvivo 11 interface for a project named 'dammy project 1.nvpx.nvp - Nvivo Pro'. The top menu includes FILE, HOME, CREATE, DATA, ANALYZE, QUERY, EXPLORE, LAYOUT, and VIEW. The 'Sources' pane on the left shows a tree view with 'Interviews with BALWD' selected. The main table lists nodes with columns for Name, Nodes, References, Created On, Created By, Modified On, and Modified By. The text view below the table shows the content of a selected node, including questions and answers about diabetes causes and knowledge.

Name	Nodes	References	Created On	Created By	Modified On	Modified By
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BALWD#12	36	39	19/02/2018 17:14	DA	19/02/2018 17:15	DA
BALWD#13	25	26	19/02/2018 17:15	DA	19/02/2018 17:15	DA
BALWD#2	44	48	19/02/2018 17:13	DA	19/02/2018 17:13	DA
BALWD#24	38	40	19/02/2018 17:15	DA	19/02/2018 17:15	DA
BALWD#3	26	27	19/02/2018 17:13	DA	20/02/2018 13:31	DA
BALWD#4	23	24	20/02/2018 15:09	DA	20/02/2018 16:38	DA
BALWD#5	28	28	20/02/2018 16:54	DA	20/02/2018 16:54	DA
BALWD#6	22	24	20/02/2018 17:34	DA	20/02/2018 17:34	DA
BALWD#8	46	52	19/02/2018 17:14	DA	19/02/2018 17:14	DA

Briefly describe what you know about type 2 diabetes? Causes?

This is where it becomes funny because after 25 years I should know what it is [laughing]. Type 1 can be controlled by a tablet, and type 2 is insulin dependent, but I might have switched it around. I think its cause when the body does not have enough insulin to regulate sugar intake or the breakdown of sugar. The body requires additional support to control the sugar, which is when tablet or insulin then needs to be taken to help. It is either limited or lack of insulin, which is hormone deficiency. You are prone to infection quickly because the body immune becomes weak and overworking itself and not able to withstand additional pressure. There is also potential blindness from glaucoma and affects the extremities like hands, feet, and body doesn't heal as fast as normal person.

Where did you get the knowledge from?

It started from families, books, doctors, information from the internet, a lot of materials from hospitals.

Do you think your diabetes is hereditary?

Yes, I think it is hereditary to a certain extent. If a parent has, it is likely to be passed down to children. If the children lifestyle and activities are not monitored, they end up having it just like you.

Do you think lifestyle in the United Kingdom could impact on developing type 2 diabetes?

No, because where I come from in Africa, health care is not as detailed as it is here. The kind of information you get over there is very limited compared to what you get here. Then, when it comes to things like feeding there is a wide range of option here especially for Africans. It

Appendix M: List of accepted papers for publications/presentation of research at conferences

Book of Abstracts: RESEARCH COMMITTEES and GROUPS (O)

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3rd ISA Forum of SOCIOLOGY

RC22-262.3

OVERLAND, GWYNYTH* (RVTS - Regional trauma competency centre Southern Norway, gwyn.overland@sshf.no)

Religious Radicalisation: The Ways of Norwegian Jihad

How do people become radicalised and what does the term really mean? "Radical" comes from the latin *radix*, root. Etymologically, "religious radicalisation" thus suggests a process of returning to the roots of a religion, to its fundamental teachings. Using both theoretical and empirical sources, this paper explores the background and processes involved in the radicalisation and recruitment of young Norwegian citizens into militant jihadi groups by means of appeals to religion and meaning incentives (Weggemans, 2015). What are they missing, the vulnerable outsiders who risk becoming the prey of scouts for extremist organisations, and what do they find?

Theoretically, the paper is based on classical sociology of religion sources, historical and religious explorations of the Crusade-jihad nexus and contemporary radicalisation research.

Empirically, the sources are interview and observation data from an on going evaluation study. The focus of the study is a longitudinal project aimed at preventing the recruitment of vulnerable young men from Norwegian secondary schools into violent extremist organisations. The paper will present preliminary findings from the research.

RC46-525.1

OVERLAND, GWYNYTH* (RVTS - Regional trauma competency centre Southern Norway, gwyn.overland@sshf.no)

The Radicalization Awareness Workshop – Providing Analyses and Interventions for Marginalised Lives and Communities?

Led on by the European Radicalisation Awareness Network (RAN, www.ran.eu) competency milieux in Norway have been mandated to implement the RAN prevent workshop among frontline helpers. This paper will briefly present the workshop and our experiences with implementation.

The work of analysis and intervention in this field is often divided into two main areas: 1. Prevention, involving social and political transformation as well as interventions with marginalized youth, and 2. De-radicalisation - involving disengagement, reintegration, mentorship and exit programmes.

Prevention is the focus for the RAN workshop. Does the workshop help workers to redeem disaffected youth? Does it give them adequate tools for effective interventions? These questions will be addressed in the presentation of the workshop. It is in the second area, de-radicalisation, that the counter narrative motif becomes central. ISIL appears to be "winning the narrative war", winning the hearts and minds of thousands of young people from 80 countries, succeeding where Al Qauida failed. ISIL narratives weave together historical symbols, beliefs and core grievances with the narrative of a global caliphate - an Islamic Camelot if you will (Lavoy et al., 2014). How to meet the challenge and supply satisfying alternative narratives?

The paper explores the common ground for prevention and re-integration from a clinical sociology point of view. Both prevention and re-integration initiatives must be informed by an understanding of why people actually take the step from mainstream to marginal - loneliness, alienation, fear of never belonging, lack of a belief in a future, lack of meaning. Recent research indicates that these problems are the same for returning Jihadis as for disaffected youth (Weggemans 2015, Harris, 2014). Both prevention and re-integration posit strategies for meeting these challenges.

RC15-JS-26.6

OVSEIKO, PAVEL* (University of Oxford, pavel.ovseiko@medsci.ox.ac.uk)

EDMUNDS, LAUREL (University of Oxford)
BUCHAN, ALASTAIR (University of Oxford)

Barriers and Facilitators to Women's Advancement and Leadership in Academic Medicine

Academic medicine is currently characterised by the underutilisation of women's talent and potential, especially, at senior levels and in leadership roles. This presents a serious threat to the quality and international competitiveness of the future health workforce. In order to identify barriers and facilitators to women's advancement and leadership in academic medicine, we conducted a systematic

be more interested in teaching and clinical work than research; women may lack career advancement and leadership skills; there is a lack of adequate mentors and role models for women; women may experience gender bias and discrimination; the culture of academic medicine is less supportive to women; work-life integration is harder for women than men; women are more likely to leave academic medicine than men.

Medical schools and university hospitals should take immediate action to eliminate all forms of gender discrimination and unconscious bias. Strategies and interventions aimed at providing women with the necessary support to increase their research productivity, with adequate mentors and role models, and with opportunities to develop career advancement and leadership skills may encourage more women to stay and seek senior and leadership roles in academic medicine. Institutions can better align research, teaching, and patient care in academic careers and develop more flexible working conditions for both genders. High-quality studies are needed to monitor and evaluate experimentally such strategies and interventions.

RC15-190.7

OYEWOLE, DAMILOLA* (Nottingham Trent University, damilola.oyewole2010@my.ntu.ac.uk)

The Role of Culture and Health Beliefs in Diabetes Self-Management Among Black African Community in the UK

THE ROLE OF CULTURE AND HEALTH BELIEFS ON DIABETES SELF-MANAGEMENT AMONG BLACK AFRICAN COMMUNITY IN THE UK

The research draws on a qualitative study to identify the impact of cultural beliefs on self-management behaviours and the significance of sociocultural approaches to health and illness among Black African people with type 2 diabetes. The study will examine lay perspectives and how they can contribute toward reformulating diabetes management policy in the UK in order to reduce health inequalities.

Type 2 Diabetes is a significant public health issue and one of the growing health problems particularly among Black African community, which presents a multi-faceted challenge to health care systems and expenditure in the UK. There are evidences that people from African descent with type 2 diabetes has poor health outcomes. Behavioural changes approaches to health promotion have increasingly been influenced by social, economic and collective model of health. However, the role of culture and health beliefs is yet to be integrated into such an approach when working with the Black African community in the UK. Realizing the multi-faceted nature of type 2 diabetes, integrated, cohesive and holistic approaches shaped by a sociocultural perspectives are important for promoting self-management practices among people with type 2 diabetes to avert any long-term complications, improve diabetes care delivery and reduce health inequalities.

Data will be collected through interviews conducted amongst the Black African community who live with type 2 diabetes and then, also, health practitioners to examine the difference in cultural understanding and interpretation of diabetes self-management behaviour within the cultural group. Better understanding of the relationship between the contextual determinants of healthy behaviours and outcomes among people with type 2 diabetes could facilitate the development of culturally sensitive interventions programmes that can help to modify beliefs, assist acceptability and support self-management lifestyle among this population.

RC24-303.1

OZAKI, RITSUKO* (Imperial College London, r.ozaki@imperial.ac.uk)

Shifting Household Activities at Peak Demand

In order to supply electricity, demand of which varies daily and seasonally, generation capacity must be able to meet peak demand. To avoid potential shortages it is useful to identify households who would be willing to 'shift' their energy-intensive activities so as not to use electricity at peak times (Strbac, 2008). This paper reports on the findings of a 'dynamic' time-of-use tariffs trial conducted in London, UK, and explores how householders responded to dynamic tariffs. Unlike 'static' time-of-use tariffs, which are regular and predictable, dynamic time-of-use tariffs are irregular and unpredictable, because they are based on renewable energy, such as wind power, and tariffs change according to the availability of electricity from the renewable source. A recent study of time-of-use tariffs found that people dislike the unpredictability of tariffs and that dynamic tariffs are the least popular option for consumers unless an automation feature is added (Fell et al. 2015). Similarly, research has identified a number of issues that limit people's

List of Publication/conference presentations

Oyewole D., 2016. Exploring the influence of culture and health beliefs on self-management behaviour among Black African communities in the UK. Presentation at the 3rd ISA Forum of Sociology, Vienna, July 10-14, 2016 (Accepted for publication).

Oyewole D., 2016. The role of Culture and Health Beliefs on diabetes self-management among Black African communities in Nottingham. Poster presentation at EMUA Conference 2016 – Inspiring futures September 1, 2016, Loughborough.

Oyewole D., 2016. Social Anthropology and diabetes self-management behaviours. Presentation at the University of Minnesota, Duluth, USA. September 2016.

Oyewole D., 2016. Influence of cultural transition on health seeking practices among Black African communities living with type 2 diabetes in the UK. Presentation at Nottingham Trent University, School of Social Science seminar. December 2016.

Oyewole, D. and Gibson L., 2017. Exploring the epistemological challenges of cultural perspectives of diabetes self-management behaviour among Black African communities through ethnography. Presentation at EASA Medical Anthropology Network 2017 Biennial Conference Network Meeting, Lisbon, Portugal. July 2017 (Accepted for publication).

Oyewole, D. and Gibson L., 2018. Towards a person-centered healthcare system: experience, voice and needs of people living with type 2 diabetes among the Black sub-Saharan African communities in the UK. Presentation at the XIX ISA World Congress of Sociology, Toronto, Canada July 15-21, 2018.

Oyewole, D., 2018. Cultural drivers of health-seeking behaviours among Black sub-Saharan Africans living with type 2 diabetes: Ethnographic perspectives. Presentation at the XIX ISA World Congress of Sociology, Toronto, Canada July 15-21, 2018.

Appendix N: Gantt Chart

