Meaning through Caregiving: A Qualitative Study of the Experiences of Informal Carers

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Abstract

This article reports the findings of a qualitative investigation of the way people find meaning through caregiving. It draws on the results of in-depth interviews with 37 informal carers and 11 stakeholders in Nottinghamshire, England. For most respondents caregiving involved looking after family members – for example, husband or wife, father or mother, young or adult children, and mother-in-law. The meaning that respondents found through caregiving motivated them to cope with the difficulties associated with looking after a person in need. This research found that most informal carers operate with long-standing gender-based understandings of their role, creating a potential risk that using gender-neutral terminology when referring to family members may obscure the subjective values that carers attach to informal caregiving and lead to role confusion. Moreover, although informal carers typically feel obliged to take care of family members in need and may value this role, they often require additional support from the state to reduce the pressures associated with caregiving and to enable them to continue to lead a meaningful life both within and beyond their caring role.

Key words: meaning through caregiving, marital commitment, parental duties, caregiving and culture, state support

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Introduction

This article examines the relationship between meaning in life and informal caregiving. Informal carers are those who 'look after, or give any help or support to family members, friends, neighbours or others because of either long-term physical or mental ill health/ disability or problems related to old age' (Office for National Statistics, 2011, p. 7). They have offered a wide range of assistance to care recipients, including emotional support, personal care, managing medication and help with eating, drinking, getting dressed, preparing meals, doing shopping and household cleaning. In 2015, there were 6.8 million carers in the UK and more than 23% of them had provided more than 50 hours of care per week, saving the government £132 billion a year (Buckner and Yeandle, 2015). However, caregiving is a very demanding task and can have 'a catastrophic effect on carers' incomes, health, wellbeing and relationships' (Carers UK, 2015, p.6). Over the past two decades, there is an increasing number of studies investigating protective factors that support caregivers to sustain their role, mediating stresses arising from caring duties. 'Finding meaning' has been identified as a key factor contributing to caregivers' well-being (Carlisle, 2010; Kim, et al., 2015). Thus, promoting meaning in life has become a promising focus for caregivers' intervention.

Meaning has different definitions. It can be 'the web of connections, understandings, and interpretations that help us comprehend our experience and formulate plans directing our energies to the achievement of our desired future' (Steger, 2013, p. 166). Regarding caregiving, the definition of meaning is 'positive beliefs one holds about one's self and one's caregiving experience such that some benefits or gainful outcomes are construed from it' (Giuliano et al., 1990, p. 2). The existing literature on meaning in caregiving mainly comes from psychological studies that focus on micro-psychological processes and counselling issues instead of health and social care issues. Most research studies also investigated caregivers who looked after someone only with a specific health problem. This study enhances our understanding of meaning in caregiving by studying the experiences of different types of caregivers in a single study. It also discusses the implications of meaning in caregiving to social care policies.

Finding Meaning and Caregiving

Since the late 1990s, researchers have investigated the strengths and positive elements that support informal carers to tackle adverse circumstances. 'Finding meaning' has been identified as a positive psychological resource variable as well as a source for better coping and adaptation (Noonan, et al., 1996; Farran, et al., 1997). Viktor Frankl's 'Man's Search for Meaning' is the first and also the most influential book in this area. He argues that human beings need to find meaning; indeed, this is 'the primary motivation' in their lives (2011, p. 80). Meaning is unique to a particular individual, and it is fulfilled by that individual, and only that individual, completing a particular task. Frankl (2011, p. 88) explains,

> [e]veryone has his own specific vocation or mission in life to carry out a concrete assignment which demands fulfilment. Therein he cannot be replaced, nor can his life

> be repeated. Thus, everyone's task is as unique as is his specific opportunity to implement it.

A person may also seek meaning in life 'by experiencing something – such as goodness, truth and beauty – by experiencing nature and culture or, last but not least, by experiencing another human being in his very uniqueness – by loving him' (Frankl, 2011, p. 90). Indeed, seeking meaning in life helps a person to achieve actualisation. In Frankl's (2011, p. 89) words,

> being human always points, and is directed, to something, or someone, other than oneself – be it a meaning to fulfil or another human being to encounter. The more one forgets himself – by giving himself to a cause to serve or another person to love – the more human he is and the more he actualises himself'.

In relation to caregiving, he claims that a person may embrace suffering because it is precisely through experiencing hardship that a person may find meaning in life. He writes: 'man's main concern is not to gain pleasure or to avoid pain but rather to see a meaning in his life. That is why man is ever ready to suffer, on the condition, to be sure, that his suffering has a meaning' (Frankl, 2011, p. 91). In short, finding meaning can change a person's views and feelings in time of adversities, motivating him/her to endure hardships in order to achieve a valued purpose.

The concept of meaning in life has been further developed by researchers since the 1990s. After analysing the experiences of carers who looked after older loved ones, Noonan, et al. (1996, p. 313) reported that caregivers found meaning from 'Gratification and Satisfaction with the caring role, a sense of Family Responsibility/Reciprocity, the Friendship and Company which caregiving provided, and a commitment to Doing What needs to be Done'. Moreover, meaning in caregiving, pointed out by them, includes cognitive and emotional dimensions. The former is 'the beliefs that caregivers hold about their experience' and the latter is 'the satisfaction they find with the role and with its benefits and rewards' (Noonan, et al., 1996, p. 325).

Although research studies have concluded that finding meaning helps caregivers to make sense of their daily caring tasks, encouraging them to use new coping strategies while facing challenges, there are two issues that need further exploration. Firstly, most studies in the area of meaning in caregiving were conducted by psychologists, with main concerns on cognitive processes of respondents and the implications to stress models, behavioural therapy and counselling (Giuliano et al., 1990; Farran et al., 1997). There are few discussions about the implications of finding meaning to health and social care policies. Secondly, the respondents in most studies were caregivers who looked after a specific group of cared-for persons such as cancer patients, older people with dementia, palliative care patients, and children with a disability (Carlisle, 2010; Kim, et al., 2015). As a researcher pointed out, the finding meaning in her study 'is not generalizable to carers in the context of other life-threatening diseases' (Carlisle, 2010, p. 762). This study will enhance our knowledge of the 'meaning in caregiving' by studying the experiences of caregivers who were looking after different types of cared-for-person in a single study. It also will discuss the implications for social care policies.

Research Methodology

Data of this study was generated from a qualitative investigation of the needs of informal carers in Nottinghamshire, England. The research team examined various caring issues from a wide range of carers shown in the following table, all of whom had been identified by the local authority as ‘seldom heard’ groups, with their needs requiring further investigation:

Table 1: The type and number of carers of this study

Carer group	Number of carers
Black and Minority Ethnic (BME) groups	8
New migrants/asylum seekers	3
Substance misuse carers	5
Young carers	3
Mental health	5
Carers in rural/isolated areas	3
Gypsies and traveller communities	3
Armed forces veterans	3
Lesbian, gay, bisexual and trans-sexual (LGBT)	2
People who have acquired brain/head injury	2
Total	37

In-depth interviews were conducted with two groups of respondents: 37 informal carers and 11 stakeholders representing non-governmental and governmental agencies that offered services to carers. The inclusion of stakeholders aimed to gather additional information on the caring experiences of the informal carers from the perspective of service providers.

The fieldwork was carried out between 25 July and 5 November 2016, following approval of the research ethics protocol by a university ethics committee and completion of a risk assessment. Among the 37 respondents, 32 took part in individual face to face interviews and 5 participated in telephone interviews due to their requests. The face to face interviews were conducted in public places near the respondents’ home such as service providers’ venues, public libraries, and cafes. As for the stakeholders, 10 out of 11 interviews were individual face to face interviews and one was conducted by telephone at the request of the respondent. The carers were recruited mainly through referrals from Nottinghamshire County Council, with the support of its partner organisations, as well as through researchers making contacts via email and telephone. A small number of respondents referred themselves to the research team, after reading the promotional literature relating to the research.

The main characteristics of the 37 respondent carers were as follows.

- 28 were female and 9 were male.
- 21 were between 18 and 64 years of age, 13 were over 65 years of age, and four were under 17 years of age.
- Nearly one third of respondents had been taking care of their husband (nine people) or wife (three people), eight had been looking after their son or daughter, five their mother, one their father, three their partner, two their brother, two their mother-in-law, while four had been taking care of persons related to them in other ways.
- 26 were born in the UK and 11 were born in other countries, including two from India and the remainder from West Germany, the Caribbean, Jamaica, Ethiopia, Nigeria, China, Hong Kong, Pakistan and Mongolia.
- 11 respondents were categorised as a home-maker, another 12 were retired; six worked part-time, three worked full-time, three were students and two were self-employed.

Carers in this study were asked what health problems that the cared-for-person had and the results are listed in the following table:

Table 2: The health problems of the cared-for-persons

Health problem of the cared for person	**Number**
physically disabled	2
head injury	2
dementia	5
alcohol/illicit drugs dependency	6
mental health illness	10
Multiple health problems	
limited mobility and hearing problems	1

multiple sclerosis and memory loss	1
arthritis and experienced pain in wrist and back	1
chronic spinal muscularity with limited mobility	1
autism, attention deficit hyperactivity disorder (ADHD) and epilepsy	1
short-term multiple sclerosis and a brain tumour	1
a physical disability, autism and a demand avoidance disorder	1
head injury and limited mobility	1
a physical disability and an aphasia	1
sight and hearing impairments	1
mental illness and a physical disability	2
Total	37

Of the 11 stakeholders, two were workers of two statutory agencies, seven were workers of voluntary and community organisations, one was a leader of a Christian church and one was a co-ordinator of a rights group. Their age range was from 27 to 53 years. Eight of these respondents were women, two were men and one did not answer the question about gender. Regarding their ethnicity, nine were 'White', one was 'Black' and one was 'Chinese'. Three respondents were born outside of the UK: the first came from Romania, the second from Somalia and the third from Hong Kong. All three had been living in the UK for more than 10 years.

All interviews were digitally recorded and transcribed verbatim prior to analysis. Content analysis was adopted to examine the interview data. Several main themes were identified, including 'caregiving & marital commitment', 'caregiving & parental duties', 'caregiving & young carers' motivations', 'caregiving & culture' and 'caregiving & wellbeing'. The following section will explain the details of these themes based on the interview data.

Key Findings

All names presented in this article are pseudonyms and codes are used to indicate data from particular respondents. For the 37 carers, their codes are from 'R1 to R37'. For respondents who were stakeholders, their codes are from 'W1 to W11'. The carers were asked how they felt about looking after another person. Their responses indicate, first, that they found meaning through caring informally for others and, second, that this meaning is associated with fulfilling their commitments and duties.

Caregiving and Marital Commitment

Interviewees who took care of a wife, husband, or partner developed a sense of meaning mainly through fulfilling marital commitments. In her experience of looking after a husband of 65 years of age who had a physical disability and suffered from aphasia, Margaret felt that her role as a carer was part of her marital relationship and therefore could not be called ‘a duty’: ‘We have been married for 43 years. I don’t see it as a duty, as I am helping my husband who is also my friend’.

Joshua, his 42 years old wife suffered from a mental health problem, believed that marital life was full of both happiness and suffering:

> Being married to her, it's all part of the ‘for better or for worse’. There's a sense – by [the] way you've just got to it – sounds a bit cold this, but [you] grit your teeth and get on with it. But sometimes that's probably the most caring thing you can do. Because you have got to put your teeth [in] and get on with it.

Joshua was aware of the difficulty in fulfilling his martial commitments. It was through this process that he found meaning in caregiving. Joyce also found meaning in care through the loving relationship she enjoyed with her husband, who had been diagnosed with chronic spinal muscularity and had limited mobility. As she stated, ‘I love him and I never change it’.

The attitudes of non-British respondents to looking after a husband or wife were similar to the attitudes of British respondents quoted above. Rebecca came from the Caribbean and was looking after her husband, who was 83 years of age and suffering from dementia. She emphasised that, as his wife, she should take care of her husband. As she put it, ‘if I am capable of doing it myself, I [would] rather do it myself. He knows me: he understand[s] what I am telling him. He does what I [tell him] because he knows I am not going to tell him wrong’. Meaning through caregiving had become a driving force for her to overcome the negative consequences of looking after another person. As she stated, ‘regarding the negative impact, I don’t regret it’.

Similarly, Amelia was looking after her husband, who was 83 years of age and suffered from dementia and limited mobility. She felt that she ‘should look after him’ (R5). Marital commitment was also an important motivation for Victoria and Bethany. Victoria, who came from India, believed strongly that it was her duty to take care of her husband, who was suffering from dementia: ‘I am the closest one; of course it should be me. We have been married nearly 56 years’ (R7). Bethany, who came from Ethiopia, also believed that it was her duty to care of her 46 years old husband, who had a physical disability and limited mobility (R9).

The evidence above shows that marital commitment was a source of meaning for those respondents who were caring for a husband or wife and was the driving force that enabled them to overcome the adversity that they faced when caring for another person. It also shows that the concept of marital obligation was shared by both British and non-British respondents.

Three respondents referred to the cared-for-person as ‘partner’. For example, Sophie (R14) claimed that it was her duty to take care of her 36-years-old partner who had an alcohol problem. Two other respondents (R31 & 32) considered their partners as their friends and were happy to support them. In short, some married respondents found meaning through fulfilling their martial commitments, while some carers obtained meaning by helping their partners who were treated as their friends.

Caregiving and Parental Duties

For those respondents who had children, the meaning of care was bound up with fulfilling their duties as parents. Even though having to take care of a four-year-old son who was suffering from multiple health issues, including a physical disability, learning difficulty and a hearing problem, Alice stressed: ‘I still love him unconditionally, and I feel that as much support that I can give him, would help him as well (R10). I feel like I have been given this assignment to do, and I just have to carry it out well, so I feel good as a mum’.

Similarly, Mary stated that it was her duty to take care of her son, who was 40 years old and had a mental health problem and a physical disability: ‘Well, it is with obviously me. Nobody else has got the responsibility (R28). I’m the parent and it's what you do ... I feel like I'm doing the best I can really. I just feel as if I'm doing a good job. I can't think of anything at the moment, no’.

Although caregiving was time-consuming, emotionally draining and financially demanding, Florence found that she and her son, who was 38 years of age and had a mental health problem and ADHD, were ‘very close and have an excellent relationship (R30). By supporting her son, who was 28 years of age, drug dependent, and had a mental health problem, Shannon aimed to ‘make sure that he is safe and [all] the rest of it’ (R29).

The principle of parental duty was also expressed by Norman from Pakistan, who was taking care of his daughter, who was 27 years of age and had multiple health problems, including a physical disability, autism and a demand avoidance disorder (R6). As he emphasised, ‘I do it because it is my family, but otherwise it is quite depressing. This job is never going to end’.

These responses highlight the importance of parental duty and blood relationship in caregiving. As the respondents emphasised, they gave birth to their children, and because they had done so, they felt that they had an obligation to look after them, regardless of their children's age and health condition. They found meaning by fulfilling their parental duties and, at the same time, developed a closer emotional bond with their children when caring for them.

Caregiving and Young Carers' Motivations

The young carers in this study found meaning by looking after parents or siblings who were unwell. Megan, who was 14 years of age, was happy to look after her younger brother, who suffered from autism, ADHD and epilepsy (R21). As she stated,

> I don't mind doing it. It helps out my parents, and because I know how he is, especially with like before, if he doesn't like them, it's hard. So I help them out. Also, they have household jobs and with Peter as well; I don't mind doing it … I feel good about doing it. (R21)

In this case the positive meaning attached to caring is thus rooted in the wider family, with caring activities seen as contributing not only to the recipient of the care but other family members who share responsibility.

Other young carers regarded taking care of their mother as a part of daily life. Ella, who was 16 years of age, was taking care of her mother, who suffered from a head injury and had limited mobility. In her view, caregiving 'just feels normal; it's what I've done for as long as I can remember' (R24). Chloe, who was also 16 years of age, valued looking after her mother, who had multiple health problems, including mental illness and a physical disability. She pointed out, in particular, that her caregiving made her more mature than her friends, and that through this activity she had gained useful household skills such as cooking, cleaning and sewing (R25). Hannah, who was 14 years of age, saw caring for her mother as an expression of reciprocity between parents and children: '[s]he is my mum … [she] has given birth to me, and now it is time for me to pay back to her, as I know that, without her, I … [wouldn't] be here on this earth' (R23). In short, the evidence has illustrated that the young carers obtained 'meaning' from looking after sick family members. They also treated this as part of their daily life.

Caregiving and Culture

For some respondents, the meaning that they found through caregiving was related to the values of their cultures. For example, Alan said that he did not expect to receive financial rewards when taking care of his son, who was 19 years of age and had alcohol and mental health problems. As he emphasised, 'I'm Indian, so I think that I don't see that. It's my duty' (R8). As he explained further, from 'a purely parenting perspective and cultural perspective, I think … no [financial rewards] … because he's my son, he's the person we love and it's our job to do it' (R8).

The impact of culture on meaning in care was also expressed by other respondents. Cecile came from Jamaica and was looking after her mother, who was 83 years of age and had limited mobility and hearing problems. She believed that it was her 'duty to look after her' (R4). She indicated that cultural expectations had influenced her decision to look after her mother: 'Well, I think these depend on a culture thing … because I think, coming from an African–Caribbean family born and bred – my mum and dad are from Jamaica – I think [it's] just … that you look after your parent …' (R4).

Coming from Mongolia, Wendy was looking after her mother-in-law, who was 85 years of age and suffering from dementia. She explained that both she and her husband chose to take care of her mother-in-law at home:

> 'I chose to be her carer. Mum didn't want to go into a residential home. My husband used to look after her, but he got really bad depression so I took over. It took a big load off my husband's shoulders and made all three of us happier'. (R11)

In many Asian countries, the daughter-in-law is culturally expected to take care of the mother-in-law. It is also common for a married adult to live with their parents. Wendy's (R11) views were the expression of this tradition. Indeed, it should be noted that all the ethnic minority respondents in this study were living with the person for whom they cared and that, of these, two women were looking after their husband's mother. In short, some ethnic minority respondents obtained meaning by fulfilling the traditional, culturally expected caring role within the family.

Caregiving and Wellbeing

Some respondents believed that they could provide better care for their loved ones and that their role could not be replaced by other people. Based on her experience of looking after her young son, who suffered from multiple health problems, Alice emphasised that

> nobody can actually look after him the way I do. That's what I think, because I know him more. Apart from that, he is mine. I can't hurt him because I know that he belongs to me. I gave birth to him. Outsiders will do the same but, trust me, it might get to the point where they feel frustrated because 'you're not mine'. I think there might be people out there who could look after him better, but personally I feel nobody can actually look after my son like me. (R10)

Similarly, Cecile stressed that only she could make sure that her mother was safe and properly cared for: 'I know [that] [if] my mum is with [me], she is just safe; I know she [is] [being] taken care of by myself. I see her every day and she is ok …' (R4). A similar view was expressed by Amelia, who was happier that she was the person who was caring for her husband: 'I know [that] if I look after him, he is safe and well treated' (R5).

The meaning that young people found through caregiving was enhanced by their parents' happiness. As Chole stated, 'I enjoy it because they're my parents and I enjoy making them happy' (R25). In short, some respondents found meaning in care through the knowledge that they were improving the wellbeing of their loved ones. In particular, they felt that their role as caregiver could not be taken over by other people.

Discussion

Having explored the meaning that people find through the activities of caregiving, this section will discuss the implications for public policy and practice.

Caregiving and Traditional Family Relationships

Most of the respondents in this study found meaning through looking after family members – for example, husband and wife and parents and children. They took on the role of caregiver in fulfilment of their role within a particular type of social relation. For the married couples, caregiving was the fulfilment of their marital commitment to providing long-term mutual support to their partner. For the parents, caregiving was the fulfilment of their responsibility to take care of their children, who had various health care needs. For the young carers, caregiving was the fulfilment of their role as a son or daughter in supporting parents or siblings who were unwell and thereby in enabling the smooth operation of the family. In short, respondents found meaning through caregiving within the context of a relationship with another family member. As the respondents confirmed, the meaning that they found through caregiving motivated them to cope with the physiological, psychological and financial strains associated with providing care to another person.

It should be noted that both white British *and* ethnic minority respondents found meaning through caregiving within the social relation of husband and wife. In other words, the principle of marital commitment was upheld by BME respondents. Marriage, and its associated value of long-term mutual support, had motivated the BME respondents to look after their loved ones, even in times of difficulty.

In recent years, there have been discussions about using gender neutral terms, such as spouse and parent, in place of ‘husband, wife, mother and father’ within new legislation (*timesofmalta.com*, 2017). It has also been reported that neutral terms such as 'spouses and partners' would be used in place of 'husband and wife' on social security benefit and immigration forms in the UK (*The Telegraph*, 2012). Indeed, given that respondents in this study understood caregiving within traditional familial and marital relations, referring to themselves and the people for whom they cared as ‘husband and wife’, ‘son/daughter and mother/father’ and ‘daughter-in-law and mother-in-law’, there is a potential risk that a change of terminology may undermine the tradition of caregiving within familial and marital relations and lead to role confusion since respondents would have to find, and develop, a new identity within a social environment of gender-neutral references. Therefore, policy makers may need to study the implications for informal carers of a change to the referencing terminology and examine the possible impact on traditional caring relationships.

The second issue arising from the findings of this study is the concept of ‘carer’. Because respondents found meaning through caregiving within a particular type of social relation, they tended not to perceive themselves as a carer and did not want to be referred to as a carer. For example, Rachel, who was taking care of her husband, declared:

> I don’t classify it as caring at all. He’s my husband. I got together with him and he had already got PTSD (post-traumatic stress disorder). I knew what I was getting into; I’d just accepted it. I knew nothing different. It’s just part of our life. (R36)

According to some stakeholders, service users thought that it was their duty to take care of relatives and did not consider themselves to be a carer. As one frontline worker emphasised, ‘I can’t even say how many conversations I must have had where people argue the point that “I am not a carer”’ (W9). She explained further:

> I suppose for most of the ones we meet, they don’t consciously take on the caring role, do they? I mean, most of them become a carer through things like a stroke or, and it's just their duty, or I suppose they feel it’s their duty as a husband, wife, parent, whatever. (W9)

In short, the official term ‘carer’ in policy documents is not an appropriate term to use to express the reality of informal caregiving and the meaning that people find through providing care to a loved one on an informal basis. Moreover, if the term ‘carer’ was understood to mean ‘paid care worker’, this would undermine the value of the informal support that people provide within familial and marital relations; in short, informal carers would feel devalued. Therefore, social services agencies and their workers need to be aware of the problems that may arise when the term ‘carer’ is used to refer to informal caregiving.

Caregiving and State Support

The findings of this study have demonstrated that support from the state is essential to sustaining the possibility of finding meaning through caregiving. According to some respondents, health agencies need to be involved in caring for loved ones who have serious health problems. Ann, for example, was taking care of an adult son suffering from a mental health condition: ‘I'm not for one minute saying that families and carers shouldn't be involved or shouldn't want to be involved, but if it's a serious illness, then I suppose it's the authorities’ (R20).

Having declared that it was her duty to take care of her alcoholic partner, who was 36 years of age, Sophie still expressed a need for external support: ‘You feel like you're on your own. I did need help, especially emotionally; you do you need that support behind you’ (R14). She complained that more information needed to be provided for carers like her:

> I think, to be honest, I know you're lucky to have the NHS but you go to the doctor's and they can't really point you in the right [direction]. I think they should have more information … and point you in the right direction, if that makes sense, because, at the

> end of the day, it's still an illness, isn't it? So I do think there should be more information at places like that, even if it's leaflets or whatever's best. (R14)

The expectation of support from the state also came from ethnic minority respondents, contrary to widespread assumptions that ethnic minorities and particularly South Asians prefer to look after their own. For example, Alan, who looked after his son, said:

> I need the support of professionals and I need the support of the state to look after him – sometimes or maybe all the time. But at this moment in time, I am managing. With the support of people that I have found, I've been looking for the support … Yes, I've been actively seeking support. (R8)

Lily, who came from mainland China and was taking care of her mother-in-law, stated: 'I don't mind looking after her but I have no income because all the time I am with her, for 24 hours, so [that] I can't … do any[thing] else' (R2).

The expectation of state support was higher among respondents who were either relatively old or were in poor health. For example, 85-years-old Amelia, who suffered from arthritis and experienced pain in her wrist and back, needed external support on certain days of the week. She pointed out: 'I feel I should look after him [her husband] while I am here but I would like a little bit of help' (R15). A young carer explained that financial support from the state could support her in her caring role: '… the money will help me out when I need to help mum with shopping and other stuff that she needs' (R22).

Unfortunately, carers are unable to get sufficient support because of the UK government's budget cuts since 2010. In 2011, local government's budget was reduced by 27%. Social welfare expenditure was cut by £18 billion between 2010 and 2015 (Bassel and Emeijulu, 2018). Many carers faced financial problems, with more than 40 per cent having to cut back on the use of heating due to debt and 20 per cent found it difficult either to pay the rent or to settle mortgage payments (Carers UK, 2015).

Therefore, effective support from the government is essential to address carers' psychological needs. Although informal carers are entitled to respite care following the introduction of the Care Act 2014, 40% of them did not have a break over one year (Carers UK, 2017a). Thus, action plans are required to enable carers to take a break from their caring duties. Moreover, extra financial support for informal carers to participate in leisure and social activities can reduce their loneliness and promote their psychological well-being (Carers UK, 2017b).

Caregiving and Culture

For some ethnic groups, the meaning that they found through caregiving has been shaped by their culture. East Asian societies have long been influenced by Confucianism, with filial piety as its core value. Filial piety helps maintain the family as a fundamental unit, enhancing solidarity between generations (Laidlawa, et al., 2009). According to Tseng Tzu, a student of

Confucius, there are three degrees of filial piety: 'The highest is the honouring of our parents; the second is not disgracing them; the lowest is being able to support them' (quoted in Fung 1983, p. 359). Mencius, a famous Confucian scholar emphasised, 'The actuality of human-heartedness is to serve one's parents' (quoted in Fung 1983, p. 125). Traditional family values still have some impact on the UK's ethnic minorities. A study found that Chinese groups in the UK 'remain invested in the concept of FP [filial piety]' (Laidlawa, et al., 2009, p. 283).

Family care is the main source of support for older people and sick family members for some ethnic minorities. In particular, a daughter-in-law is culturally expected to live and take care of a mother-in-law in countries including Japan, India and Saudi Arabia (Yamashita and Amagai, 2008; Alrashed 2017). Two ethnic minority respondents, one from mainland China and one from Mongolia, were living with, and looking after, their mother-in-law, who suffered from dementia. Although the caregiving had had a negative impact on her physiological and psychological wellbeing, Wendy was pleased that her mother-in-law was able to 'feel loved and looked after at home' (R11). Other respondents, from India, Pakistan and the Caribbean, also mentioned that the meaning that they found through looking after other people was associated with fulfilling a culturally expected duty to take care of family members in need (R4; R5; R6; R7; R8). As mentioned previously, a person may find meaning by experiencing nature and culture (Franke, 2011).

There are two issues arising from culture and caregiving from this study. Firstly, external assistance is crucial to sustain traditional caregiving practices of minority ethnic carers. For example, a Chinese carer (R2) obtained service information from a Chinese community organisation and also participated in its activities; while an Indian respondent received support from a carer group (R8). A research study in Japan found that carers who reported positive caregiving experiences had actively sought external support (Yamashita and Amagai 2008). On the other hand, a stakeholder of this study revealed that an ethnic minority carer did not want her family members to know her seeking help from a carers organisation (W8). As taking care of family members having been perceived to be a traditional duty, some respondents regarded seeking external support as a 'relinquishing their caregiving responsibility' (Yamashita and Amagai 2008, p. 229).

The two issues mentioned above imply that culture cannot be used as an excuse for the state to ignore the needs of carers with an ethnic minority background. For carer organisations, specific services can be offered to carers to overcome language barriers in accessing public services. For example, an Information Programme for South Asian Families was launched by the Alzheimer's Society. The service successfully enhanced the carers' understanding of the causes of dementia and also facilitated their use of support services (Parveen, et al., 2018). Similar programmes should be introduced to other BME groups who are taking care of family members with various health problems. Moreover, wellbeing coordinators have proven effective in some regions, based in GP clinics and hospitals and providing holistic and person-centred services to support carers and care recipients (Beech, et al., 2017). This could be launched nationally.

Another issue is the delivery of ‘culturally appropriate and language-matched’ services (Institute for Research and Innovation in Social Services, 2009, p. 1). Apart from providing cultural competency training, both central and local governments in the UK need to develop strategies to recruit and retain minority ethnic health and social care workers. It is evident that minority ethnic staff have potential to improve services and facilitate communication between carers and professionals (Mir and Tovey, 2002).

As BME organisations are playing a crucial role in addressing the caring burden of carers, their services should be supported by the state. Unfortunately, as a consequence of funding cuts, many non-governmental organisations are struggling to survive. The government’s austerity measures have particularly hit the BME organisations. For example, central government’s financial support for the Arts Council England and local councils was cut by 32% and 40% respectively from 2010 to 2015 (*BBC News*, 2015). Many BME organisations are ‘struggling to survive on a day to day basis’ (Ware, 2013, p. 25). Thus, the UK government needs to re-think budget cuts on ethnic minorities’ education, cultural and social activities. The reduction on support for BME organisations not only directly reduces support for carers who have difficulties in accessing public services but also has a detrimental impact on their cultural identity when they are caring for other people.

Conclusion

The findings of this study show that the meaning that people find through looking after other people, especially their loved ones, is what motivates them to undertake an activity that demands sacrifices. The meaning that they find through caregiving is based on the obligations arising from being part of familial and marital relations. For informal carers from ethnic minorities, the concept of family may also include close relatives beyond the concept of nuclear family. This explains why two daughters-in-law lived with and looked after their mother-in-law.

The argument of this study also contributes to current debates about changing the way that family members are referred to in legislation and other public documents. Using gender-neutral terminology may threaten the identity of informal carers, and the people who they look after, who obtain meaning within a context of traditionally understood gender roles. Furthermore, as informal carers play an important role in taking care of vulnerable citizens, it is important that the state offers sufficient material resources to enable them to continue to provide care and lead a meaningful life. In the absence of sufficient state support, the danger is that the pressures associated with looking after those in need will be overwhelming and will lead to resentment and despair. Searching for meaning is a human need that is not limited to the UK’s respondents of this study. Governments should examine what type of support can enhance informal carers’ sense of meaning in the process of taking care of older and sick family members.

The present study has implications for social work training and practice. Given more carers and cared-for persons are facing complicated mental health problems, social workers need to be equipped with sufficient knowledge in mental health illnesses and possess effective communication skills to work with mental health issues. Also, as the relationship between minority ethnic carers and their loved ones may be shaped by culturally-specific family values, cultural competency training needs to be offered to social workers. Cultural sensitivity training is particularly important in the UK because ethnic minorities 'do not constitute a homogenous group and have diverse support needs' (Institute for Research and Innovation in Social Services, 2010, p. 1). It has been widely reported that ethnic minorities have difficulties in using public services. For example, they underuse dementia services or access services later than the ethnic majority (Mukadam, et al., 2013). In order to tackle low-take up of social services, social workers need to work closely with minority ethnic organisations to launch support groups, education services and signpost carers to seek services. Social workers also need to involve ethnic minorities in service development so that appropriate support can be offered to carers to fulfil their caregiving duties (Mir and Tovey, 2002).

It should be noted that the respondents of this study came from only one region in the UK and their experiences may be affected by local particularities. It is suggested that future studies recruit respondents from different regions so that the impact of localities on respondents' meaning in caring can be examined. Despite this weakness, this study has generated valuable information on human relationships and the role of meaning in sustaining the respondents' caregiving duties.

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