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Optimising Diagnostic Pathways for Dementia Care: The Implications of Pre-Assessment Counselling

By

Marie Janes

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Dedication

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To my husband, Nicho, my son, Sebastian, and my father, Stan, whose steadfast support and sacrifices have been the cornerstone of my journey and to whom I have the privilege of being perpetually in your debt. Your belief in me has guided me through every triumph and challenge.

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Declaration

I hereby confirm that I completed this thesis independently, that I have not previously presented it to another department or university, that I have listed all references used, and that I have given credit to all additional sources of assistance.

Note on Inclusion of Disseminated Work

Conferences

Janes, M., Buckell, A., Jones, B. A., Park, M. S. A., & Badham, S. P. (2024, September 25-27). *The Impact of Pre-Assessment Counselling in Dementia Care According to Healthcare Practitioners* [Conference presentation]. International Psychogeriatric Association (IPA) International Congress, Buenos Aires, Argentina.

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Abstract

As the global prevalence of dementia rises, driven by ageing populations and increased life expectancies, the need for effective diagnostic pathways has become a public health concern. This thesis explores the role of pre-assessment counselling (PAC) in optimising the experience for people with dementia and their carers. PAC is an intervention delivered following a general practitioner (GP) referral before undergoing a formal clinical assessment for dementia from specialist dementia healthcare practitioners from memory assessment services. It provides tailored support through education and information, emotional assistance and guidance to enable people with dementia and those who care for them to navigate the diagnostic process with increased confidence and an understanding of what to expect from their dementia journey.

The research within this thesis incorporates insights from clinical psychology, neuropsychology and health psychology. It comprises several methodological approaches, including a systematic literature review, a summative service evaluation, qualitative semi-structured interviews with healthcare professionals, quantifying feelings of fear of dementia, depression, anxiety and stress in people with dementia before and after receiving PAC, and quantitively measuring the comparative benefits of PAC in carers who had received the intervention with those who had not.

The systematic literature review synthesises the empirical evidence of PAC used within dementia care pathways, noting that it enables psychological adjustment in people with dementia towards a potential diagnosis, that it supports healthcare professionals with quality service provision, and it helps to bring family members into discussions to assist them in supporting their loved ones. The summative service evaluation indicates that PAC aids in timely diagnoses through information and support provision to people with dementia so that they can make informed decisions about their care. The qualitative study with healthcare professionals reveals key benefits of PAC where people with dementia are placed centrally in their diagnosis journey, candid conversations help to build strong therapeutic alliances, and people with dementia learn through PAC delivery to accept that a diagnosis of dementia does not define them or their lives. The quantitative study involving people with dementia demonstrates how PAC significantly reduces stress following the intervention. In the mixed-methods study, the quantitative component shows that PAC benefits carers of people with dementia, significantly improving experiences of the initial appointment in the memory assessment service at the start of their dementia journey and increased levels of well-being post-diagnosis when compared with those who had not received PAC. The qualitative component echoed the measured outcomes and provided further insight by adding context.

These findings lead this thesis to recommend the integration of PAC into usual care provisions within dementia care pathways, owing to its ability to enhance person-centred care and significantly improve psychological outcomes for people with dementia and their carers. It recommends further research to determine the long-term effects of PAC across diverse groups and the requirement for a standardised approach.

Chapter 1: An Overview of Pre-Assessment Counselling in Dementia Care

Section 1: Dementia as a Concern

The introduction of this thesis is divided into two sections. Section 1 of this chapter will provide a background on dementia care, with a focus on the UK, by discussing current dementia care services and issues for patients and carers. Section 2 of this chapter will outline how pre-assessment counselling (PAC) can support and alleviate dementia-related issues and will contextualise the topics raised via signposting to individual thesis Chapters. This introductory chapter introduces PAC as a potential intervention for dementia care pathways. It discusses how it may address the current gaps and limitations in providing appropriate care to people with dementia and their carers. PAC is a service designed to support people experiencing symptoms of cognitive decline and those who care for them in the form of an appointment to prepare them for a possible diagnosis of dementia at the very beginning of their dementia diagnosis journey. Within this appointment, the dyad, consisting of the person with dementia and their carer, are offered information and guidance through the processes involved in the dementia journey and given emotional support. PAC is not a new concept, but it is applied in other healthcare services. However, its implementation in dementia care is limited so far. As such, this thesis seeks to explore the possible benefits that PAC may have when applied within this care pathway.

An overview of global dementia statistics and services

Dementia currently affects approximately 55.2 million people worldwide (World Health Organisation, 2021), represents not just a substantial global epidemic but a critical challenge to health systems, requiring urgent innovation in early support pathways such as PAC. Although there are more than 100 types of dementia, the most common types of diagnoses are Alzheimer's Disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia (Li et al., 2017). While dementia prevalence varies internationally, higher rates in high-income countries (HICs; Prince et al., 2015) contrast with the emerging patterns in low- and middle-income countries (LMICs), where changing lifestyles and demographic ageing are driving new trends (Prince et al., 2015). These shifts indicate a pressing need for adaptable interventions like PAC that can respond to evolving dementia profiles across diverse settings.

Critically examining worldwide trends and persistent gaps in dementia care provision highlights specific areas where interventions like PAC could directly reduce diagnostic inequalities and enhance early-stage support. These are evidenced through the disparities in timely access to support services for people with possible dementia, and PAC may play a pivotal role in reducing these by enabling education, support and forward care planning at an early stage. By recognising the current service provision available to people with dementia both globally and within the UK, insight is obtained as to how PAC could potentially assist in enabling early diagnosis for people with dementia and support for those who care for them within present care pathways.

Although lifestyle factors such as unhealthy diet, sedentary behaviour, and limited healthcare access have been widely identified as influencing dementia prevalence (Livingston et al., 2020), these modifiable risks are not uniformly addressed within early dementia support frameworks, highlighting a further potential role for interventions like PAC. Livingston et al. (2020) describe these as being modifiable risk factors where conditions such as the management of chronic health issues and the promotion of being physically active can play an instrumental role in both dementia prevention and its management.

While disparities in dementia care exist globally, particularly in LMICs, implementing new interventions like PAC is often constrained by limited funding, workforce shortages, and competing healthcare priorities (Patel et al., 2018). In such contexts, questions remain over who would fund additional preparatory care, especially given the pressure on already overstretched health systems. While international aid and non-government organisational support play a role in some regions (WHO, 2021), PAC may not currently be feasible without integration into existing community-based services. However, this thesis focuses specifically on a UK-based Memory Assessment Service as a case study, aiming to inform future practice in similarly structured healthcare systems. Attempts to meet the challenges related to dementia are ongoing, though these are addressed differently owing to the availability of resources and the varied healthcare systems within HICs and LMICs (Arsenault-Lapierre et al., 2023). This thesis examines an intervention that is a component of usual care in a particular NHS Trust in the UK. As such, it will explore the services offered within dementia care pathways to understand how these are delivered nationally. Providing a national-level focus on the UK's dementia care pathways allows for a closer examination of how PAC could enhance existing structures in response to both global and local needs. Examining the structure of dementia care pathways in the UK not only reveals national approaches to managing dementia but also exposes critical points where early interventions like PAC could improve diagnostic readiness and support services.

Dementia care pathways and services in the United Kingdom

Dementia is considered to be an increasingly pressing public health concern in the UK (Alzheimer's Research UK, 2023), requiring comprehensive support services and care pathways. To meet the rising numbers and needs of people living with dementia and those who support them, the National Health Service (NHS) has a developed framework, offering insight into the approach of this country in its management of a global problem. In the UK, some 982,000 people live with dementia (Alzheimer's UK, 2023) and this is expected to rise to approximately 2 million by 2050 (Prince et al., 2014). Prince et al. (2014) state that demographic trends in literature, including rising life expectancy and population ageing, are supported by dementia statistics in the UK. Timely dementia diagnoses and interventions will be essential to meet the demands that will be placed upon health and care services to improve the outcomes of people who live with dementia and those who care for them and to manage the condition effectively (Livingston et al., 2020).

While the NHS plays a central role in delivering a wide array of dementia care services for individuals and families pre- and post-diagnosis, variation in service delivery and accessibility suggests that early-stage support mechanisms such as PAC could help standardise and enhance patient experiences across regions. Table 1 illustrates an overview of the different support options relating to dementia and offers an indication of the resources that the UK has to offer at different stages.

Table 1

An Overview of NHS Dementia Support Services

Support Phase	Type of Support	Description
Pre-diagnosis	Educational resources	Provides information on symptom recognition and accessing services to support individuals and families (NHS, 2023).
	Helplines and Online Platforms	Helps to identify and name symptoms, learn about what support is available and where to go, and deal with issues associated with dementia (NHS, 2023).
Post-diagnosis	Dementia Advisors and Support Workers	Individuals who help provide information, advice, and emotional care at all stages of the dementia journey (NHS, 2021).
	Community Psychiatric Nurses	Offers specialised mental health support for people with dementia where required (NHS, 2021).
	Medical and Non-Medical Interventions	Where appropriate, it includes medication that may ease some of the symptoms of dementia and interventions for behavioural symptoms (Orgeta et al., 2022).
Carer support	Carer Training and Respite Care	Practical and emotional assistance to support carers in their caring roles (Daughtrey & Board, 2021; Larkin et al., 2021).

	Carer Support Groups	Peer support and resources for carers to manage the psychological impact of caregiving (Larkin et al., 2021).
Integrated approach	Multidisciplinary and Personalised Care	Emphasises holistic care through integrated pathways to improve the well-being of people with dementia and their carers (NHS, 2021).

While the NHS offers a structured range of dementia support services, their variability in timing and accessibility suggests an opportunity for PAC to bridge gaps particularly at the critical pre-diagnostic stage. As such, this thesis will explore and highlight the role of PAC within dementia care as its delivery continues to be limited despite its application and perceived benefits in other healthcare services (Bendick & Spicer-White, 2021; Cheston et al., 2000; Mega et al., 2020; Williams, 2004). As the number of dementia diagnoses continues to rise globally, there is an increased need for accurate and timely diagnoses (Prince et al., 2014). PAC might be able to assist with this need by enabling better experiences and understanding of people with dementia, their carers and healthcare professionals alike. It will also explore how PAC may support early diagnosis, what is meant by a timely diagnosis, and if PAC assists in mitigating present barriers to these diagnoses.

The impact of dementia extends beyond those who live with it but also upon carers who find themselves taking on new, unconsidered responsibilities (Aminzadeh et al., 2007) and also to healthcare professionals who perpetually challenge the misconceptions and stigma that are attached to dementia. As such, this thesis will also explore if PAC is considered an essential component of dementia care and with healthcare services continually evolving to meet the needs of people with dementia and their carers, it is important to understand if there is the potential for PAC to become an integral component of the care pathway.

The Impact of Dementia

Despite empirical evidence supporting PAC’s benefits in other healthcare settings, its absence from routine dementia care pathways raises critical questions about missed opportunities for improving emotional preparedness and diagnostic engagement. People with dementia and those who care for them encounter similar emotional challenges on the journey to diagnosis. Therefore, PAC should be explored within the dementia care pathway as it offers an alternative lens to person-centred care and could enhance the support and care delivered by healthcare professionals. QoL is further enabled as people living with dementia and their carers are prepared to receive a diagnosis of dementia, thereby reducing the shock should it be confirmed (La Fontaine et al., 2014). Additionally, the emotional, social and cognitive consequences require consideration when supporting the individual needs that people with dementia and carers bring to the PAC appointment.

Dementia impacts autonomy and independence owing to its neurodegenerative nature and commonly includes challenges such as impaired memory, visuospatial skills, attention, language and executive functioning (Petersen et al., 2018). Witnessing a person's abilities decline over time is distressing for both people with dementia and those who care for them (Clare et al., 2008). Healthcare professionals conduct cognitive evaluations such as the Mini Mental State Examination (MMSE; Arevelo-Rodriguez et al., 2015) and the ACE-III (Hodges et al., 2017) to help determine the type of dementia being presented and the stage it is presenting at from which individualised support care planning can take place (Bengal, 2020). Sometimes, neuropsychological assessments may need to be conducted to assist with diagnosis. Neuropsychology enables an understanding of the biological constructs of dementia, revealing neuropathological changes that disturb brain behaviour connections and functioning (Ratan et al., 2023).

There are many theoretical models to explain the impact of dementia on those who live with the condition and upon their families, including the biopsychosocial model, which clarifies how each of these domains is affected and how outcomes are shaped (Kuhn et al., 2024; Ownsworth et al., 2006). The biopsychosocial model (Engel, 1977) provides a crucial theoretical foundation for PAC by recognising that dementia's impacts are simultaneously biological, psychological, and social — necessitating early, holistic interventions. Progressive neurodegeneration, characterised by hallmark pathologies such as amyloid-beta plaques and tau tangles (Querfurth & LaFerla, 2010), underpins dementia's biological basis, reinforcing the need for early interventions like PAC that can prepare individuals for the inevitable trajectory of cognitive decline. These pathological changes disrupt neural communication and ultimately impair cognitive and functional abilities. Neuroscience contributes to this understanding by investigating the molecular and cellular mechanisms of brain deterioration, whereas neuropsychology complements this by exploring how these biological changes manifest in cognition and behaviour (Ratan et al., 2023).

Psychologically, individuals may experience anxiety, depression, or disruption to identity as they process cognitive changes (Orgeta et al., 2022). Socially, stigma and isolation can further erode quality of life and relational wellbeing. Positioned at the early stages of the dementia journey, PAC operationalises the biopsychosocial model by actively addressing biological understanding, emotional coping, and social support needs. It provides biological education on the disease mechanisms and expected progression, psychological support to help individuals process fear and uncertainty, and social support through signposting and involving carers in care planning. By addressing emotional wellbeing, cognitive preparation, and relational dynamics, PAC exemplifies the kind of integrative care the biopsychosocial model advocates for in chronic illness management (La Fontaine et al., 2014; Kuhn et al., 2024).

Person-centred care (Kitwood, 1997), emphasises the recognition of personhood, respect for individual identity, and the relational nature of care in dementia. This approach has since become foundational in dementia services, influencing ethical and clinical practices as well as the economic structuring of care. Ballard et al. (2018) demonstrated that implementing person-centred care in care home settings led to significant improvements in the quality of life for residents with dementia, as well as reductions in agitation and antipsychotic medication use. These clinical outcomes were associated with fewer hospital admissions and lower medication-related complications, contributing to cost savings for healthcare providers. Furthermore, the intervention improved staff satisfaction and reduced turnover, promoting organisational stability and sustained quality of care. These findings support the view that person-centred care offers substantial benefits beyond moral obligation, yielding positive outcomes for people with dementia, staff, and healthcare systems. In the context of PAC, embedding person-centred principles such as individualised information provision, emotional validation, and carer inclusion may offer similar benefits earlier in the dementia journey by improving service engagement and reducing crisis-driven interventions. Stern (2002) explored the concept of cognitive reserve, laying the groundwork for understanding how life experiences can shape the brain's capacity to cope with pathology. Stern (2020) later refined this by distinguishing between cognitive reserve, brain reserve, and brain maintenance. Brain reserve refers to the passive structural capacity of the brain, such as neuronal count or total brain volume, which may delay the clinical manifestation of symptoms by providing a greater buffer against neuropathology. In contrast, cognitive reserve is an active process that reflects the ability of the brain to optimise or compensate for damage by utilising pre-existing cognitive processing strategies. This reserve is developed through life experiences such as education, occupational complexity, and engagement in intellectually or socially stimulating activities. A third concept, brain maintenance, reflects the preservation of brain structure and function across the lifespan, often attributed to a combination of genetics and lifestyle factors that limit age or disease-related decline. While these distinctions have advanced the field, critiques of the reserve models highlight several limitations. One key issue is the difficulty of measuring cognitive and brain reserve independently, as factors such as education or intracranial volume may not fully capture the underlying constructs (Bartrés-Faz & Arenaza-Urquijo, 2011; van Loenhoud et al., 2020). Further, the conceptual overlap between reserve and maintenance can hinder interpretation, particularly in longitudinal studies, where resilience to decline may result from a combination of mechanisms. These theoretical distinctions are relevant to PAC, which may function as a cognitive reserve-enhancing intervention. Through psychoeducation, emotional support, and proactive engagement with care planning, PAC could foster resilience and adaptive coping strategies at an early stage in the dementia pathway. In doing so, PAC may help individuals mobilise existing cognitive resources or build new ones, supporting psychological adjustment and prolonging functional independence in the face of cognitive decline. Lastly, the social elements of health models highlight how factors such as education, access to healthcare and socioeconomic status determine and shape both the risk and progression of dementia, adding leverage to the requirement for suitable support services (Kerwin et al., 2022; Livingston et al., 2020).

The Role of Carers

Caring for someone with dementia entails profound emotional and practical challenges, as carers navigate the complexities of a progressive and highly individualised degenerative condition, reinforcing the necessity for structured early interventions such as PAC. The role of being a carer is frequently accompanied with increased levels of burden, stress and emotional distress, especially immediately following a diagnosis, as carers seek to balance their existing roles, responsibilities and identities with the new ones that often come with a confirmed diagnosis of dementia (Quinn et al., 2015; van der Lee et al., 2017).

Unsurprisingly, such challenges can impact upon the health of carers, which contribute to an elevated likelihood of developing chronic conditions, sleep disturbance and fatigue, which in turn creates further challenges concerning their capacity to manage the care of people with dementia (Ploeg et al., 2020).

Given the complex demands placed on carers, interventions such as counselling, support groups, and psychoeducation are crucial; however, the evidence remains mixed on which strategies are most effective, highlighting a gap that PAC could help address by offering individualised early support (Barrera-Caballero et al., 2021; Cheng & Zhang, 2020). However, reported outcomes vary across studies and this may be owed to their methodological differences. For example, qualitative studies such as those by Gately et al. (2002) and Francis and Hanna (2022) explore carers’ advocacy and relational roles in depth, drawing on narrative data that focus on emotional labour and contextual complexity. In contrast, quantitative studies like those by Carlozzi et al. (2018) and Miller et al. (2016) rely on standardised questionnaires, focusing on measurable outcomes such as burden or quality of life but potentially overlooking more nuanced relational aspects of caring. Mixed-methods studies attempt to bridge this gap but variation in sampling strategies, measurement tools and timing of data collection can still influence findings. These methodological differences can therefore result in varying conclusions about the nature and extent of carers' contributions. For instance, while some studies report carers as central decision-makers (Brodaty & Donkin, 2009), others present them primarily as observers or supporters (Quinn, Clare & Woods, 2010). Understanding these differences is crucial, particularly when applying research findings to practice or policy. Methodologically diverse evidence underscores the need for tailored and flexible support approaches that recognise the multidimensional and evolving nature of the carer role in dementia care. In literature, carers frequently report feelings of guilt, loss and grieving over the person they care for as they witness their functional and cognitive decline (Aminzadeh et al., 2007). These emotions demonstrate the extreme personal impact that caring for someone with dementia has, as well as the changing landscape of their relationship with their loved one (Orgeta et al., 2022). It is known that carers will often make social sacrifices in the form of meaningful activities and connections to focus on their caring duties, and this frequently results in feelings of loneliness and isolation (Kovaleva et al., 2018). Dementia impacts physical, emotional, and social well-being and this only serves to show the importance and necessity of support services, including access to respite care, which provide carers with some relief from their duties and care for themselves and their own needs (Chang et al., 2020; Song & Kim, 2021).

Given this, offering services and interventions such as counselling, support groups and psychoeducation, is imperative to ensure that carers are equipped with the tools to manage the impact of their caring role and maintain their quality of life (Barrera-Caballero et al., 2021; Cheng & Zhang, 2020). Carers are pivotal to the lives of people who live with dementia as they are frequently the first people to notice and report on functional or cognitive changes, and this is particularly helpful to healthcare professionals to enable accurate assessments and personalised care plans (Brodaty & Donkin, 2009; Carlozzi et al., 2018; Gately et al., 2002). However, carers do more than observe and report. They play a crucial part in decision-making processes, which do not include just the initial diagnosis but also possible treatment options and advanced care planning, making sure that these subscribe to the values and preferences of people with dementia (Miller et al., 2016). Given carers' central roles in advocacy and care coordination (Alzheimer's Association, 2023; Francis & Hanna, 2022), PAC must be designed to support not only diagnostic understanding but also the evolving advocacy responsibilities placed on carers. Carers provide people with dementia with emotional and social support by assisting them to participate in meaningful activities which helps reduce feelings of isolation and preserve their identity (Jetten et al., 2010; Steeman et al., 2013; Woods, 2001).

Carers are required to balance a large amount of responsibilities to maintain the emotional well-being and QoL of people with dementia, which require recognition and support. Carers of people with dementia are also their advocates and companions and are essential in their role of supporting the person experiencing cognitive decline through the journey of dementia diagnosis and at every stage of the condition whilst coping with the personal demands of such a challenging role (Quinn et al., 2015; van der Lee et al., 2017). This exploration of carers' roles and responsibilities highlights the emotional, physical, and social toll that dementia caregiving entails. It reinforces the importance of PAC as a preparatory intervention aimed at equipping carers with the information, support, and coping strategies needed to navigate their caregiving roles.

The Wellbeing of People with Dementia Following a Diagnosis

People with dementia might incur elevated depression, anxiety and distress levels post-diagnosis as they come to terms with the reality of dementia and the impact that it could have on their lives and on the lives of those of their families (Orgeta et al., 2022). They might also experience disruption to their sense of identity and relationships if they should endure mood, behaviour and personality changes (Woods, 2001). Like carers, people with dementia experience negative social implications. Bascu et al. (2022) report that feelings of shame, social isolation and stigma are commonly felt in people with dementia as they deal with societal misconceptions, negative stereotypes and attitudes towards the condition. Feelings of alienation and loneliness are compounded further by functional and cognitive abilities declining, resulting in further difficulty in maintaining feelings of connectedness and engaging in meaningful activities (Bild & Pachana, 2022; Birt et al., 2022a).

Recognising both immediate emotional responses and long-term well-being outcomes critically underscores the need for proactive interventions like PAC to facilitate psychological adjustment at the point of diagnosis. This emphasis on well-being supports the thesis' exploration of PAC as a means to enhance the quality of life by mitigating some of the distress associated with the diagnosis. Building upon this, it would be useful to identify how PAC could impact the quality of life (QoL) for people living with dementia.

Enabling Quality of Life (QoL) for People with Dementia

Quality of life (QoL) is measured across different areas, including physical, psychological, and social and emotional satisfaction with life and is an area that is considered critically important for people with dementia to maintain following diagnosis (Morrison et al., 2020; Quinn et al., 2022). Since QoL is a primary goal of dementia care, PAC can be contextualised here as being valuable in supporting this objective. While closely related to well-being, QoL is distinct in that it provides a holistic view of an individual's satisfaction and experiences across life domains, whereas well-being often refers more specifically to subjective experiences within these QoL areas. It is important to both recognise and address the components that impact upon QoL as it is essential for comprehensive dementia care provision (Gonzalez & Kirkevold, 2014). This is because by increasing or maintaining QoL, the emotional resilience and overall functioning of people with dementia is directly affected (Clare et al., 2014).

While closely related, well-being and QoL are conceptually distinct and should not be used interchangeably. Well-being typically refers to a person's subjective emotional state and includes factors such as mood, anxiety, stress, and overall psychological functioning (Bild & Pachana, 2022; Orgeta et al., 2022). It captures how a person feels in the moment and over time. In contrast, QoL is a broader, multidimensional concept encompassing physical health, psychological state, social relationships, functional ability, and personal beliefs (Gonzalez & Kirkevold, 2014; Martyr et al., 2018). While well-being is often a component or outcome of QoL, it does not encompass the full range of domains that QoL includes. In dementia care, this distinction is particularly relevant. For example, a person with dementia may report relatively high emotional well-being due to strong family support, while still experiencing reduced QoL due to physical limitations or social isolation. In the context of PAC, both concepts are important. PAC may directly support emotional well-being by reducing fear, stress, and uncertainty, while also contributing to QoL by facilitating engagement with services, maintaining identity, and encouraging meaningful activity.

Maintaining engagement with social interactions and meaningful activities is essential for the social component of QoL, which enables people with dementia to feel a sense of fulfilment and belonging (Birt et al., 2020a; Han et al., 2016). These opportunities for connecting with others and receiving social support are essential to combat the loneliness and isolation that people with dementia say that they experience following diagnosis (Bild & Pachana, 2022; Birt et al., 2022a). By proactively encouraging meaningful social connections through early signposting to support networks, PAC addresses a key contributor to post-diagnosis isolation and loneliness. QoL maintenance is an essential component of dementia care (Martyr et al., 2018) and interventions such as PAC, aim to enhance this. This thesis establishes the value of PAC as a means to holistically support people with dementia and their carers before a diagnosis is confirmed.

Finally, emotional support that validates personal experiences contributes to dignity and self-esteem. QoL and emotional well-being are enhanced through person-centred care as it prioritises the values, wishes and preferences of people with dementia, which helps to enable a sense of identity and agency (Bosco et al., 2019; Rose & Dening, 2023). Owing to its person-centred approach, PAC may help preserve identity in both people with dementia and their carers. Understanding how PAC works within dementia care pathways is important, as this can help maintain QoL.

Section 2: Pre-Assessment Counselling as a Solution

What is Pre-Assessment Counselling (PAC)?

PAC may address the gaps currently existing within dementia care, such as delayed diagnoses, reducing stigma and additional support for carers (Donegan et al., 2017; Orpin et al., 2014; Queluz et al., 2020). The necessity of early support prior to cognitive assessments is specifically addressed through PAC. Although the memory assessment services that are provided via the NHS provide a route to diagnosis and post-diagnostic care, their effectiveness and accessibility of the wider dementia care framework in the UK can be enhanced by adequately preparing people with dementia and their carers for what to expect from the diagnostic process through the use of PAC.

As formerly mentioned, the typical dementia journey starts when a person experiencing cognitive concerns discusses their issues with their GP (Phillipson et al., 2015). The GP usually conducts an assessment of their symptoms and enquires about the duration they have been experiencing them and the impact that they have on daily life, along with existing medical conditions and current medications. Following an initial appointment with a GP, a referral is typically made to a memory assessment service to conduct a cognitive evaluation with a specialist dementia clinician, and another is made for an MRI or CT brain scan (Alzheimer’s Research UK, 2023). Defining PAC and illustrating its use in other healthcare contexts reinforces its relevance to dementia care. The parallels drawn between PAC applications in fields like oncology and genetic counselling demonstrate PAC’s potential to provide anticipatory guidance and psychological support in dementia care pathways, setting the stage for the thesis’ investigation of PAC’s specific effects in dementia care.

Genetic counselling.

In genetic counselling, PAC is used to prepare individuals for potentially life-altering test results concerning inherited conditions (Mega et al., 2020). These appointments, usually led by trained genetic counsellors, provide tailored information, facilitate emotional readiness, and support individuals in considering implications for themselves and their families (Crook et al., 2017; Mega et al., 2020). The individuals who engage in genetic PAC tend to be at an earlier stage in their health journey, often asymptomatic, and face choices around prevention, lifestyle modification, or reproductive planning. The role of PAC in this setting is therefore closely tied to future planning and psychological containment. In contrast, dementia assessments often involve individuals who are already experiencing cognitive symptoms, sometimes with impaired insight or fluctuating capacity. Therefore, while both settings aim to prepare individuals for potentially distressing diagnoses, the delivery of PAC in dementia care may need to be more relational, iterative and accessible to carers. This comparison highlights how differences in patient profile and timing of intervention shape the design and expected outcomes of PAC. The transferable element lies not in the format, but in the commitment of equipping individuals with emotional and informational tools prior to diagnosis.

Oncology.

PAC in oncology is widely established as a supportive intervention during the diagnostic and treatment-planning phases, often involving detailed discussions around diagnosis implications, treatment options and emotional responses (Bousquet et al., 2015; Cheston et al., 2000). In these settings, PAC often includes the person undergoing assessment and their family, providing an opportunity to ask questions, express fears and begin making sense of the potential diagnosis. The goal is often to enhance decision-making, ensure informed consent for treatment, and mitigate psychological distress. While dementia shares some similarities, particularly in terms of long-term planning and emotional impact, key differences exist. Dementia diagnoses are often more ambiguous, with slower diagnostic timelines and progressive symptom presentation (Dhedhi et al., 2014; Brossard & Carpentier, 2017; La Fontaine et al., 2014; Livingston et al., 2020. Consequently, PAC in dementia care may require a greater emphasis on normalising uncertainty, encouraging emotional resilience, and addressing stigma surrounding cognitive decline. Although both pathways benefit from early psychosocial support, their focus and structure must reflect the nature of the condition and the anticipated trajectory.

HIV Care.

In HIV care, PAC is used to prepare individuals for a diagnosis that has historically carried significant stigma and emotional weight (Williams, 2004), and sessions typically provide information about the condition, outline treatment options, and offer emotional support in navigating disclosure and future planning. While HIV was once considered a terminal illness, the advent of effective antiretroviral therapy has transformed it into a chronic, manageable condition (Cohen et al., 2011). With timely diagnosis, adhering to treatment and psychosocial support, many people living with HIV now enjoy long and fulfilling lives, maintaining employment, relationships and community engagement (Gonzalez et al., 2011; WHO, 2021). Despite these medical advances, HIV still carries emotional and social complexities. PAC plays a vital role in supporting individuals during the diagnostic phase, helping them to process the implications of a lifelong condition (Williams, 2004). However, HIV and dementia differ significantly in terms of prognosis and treatment. Dementia, in contrast, remains a progressive neurodegenerative condition with no current cure (Petersen et al., 2018; WHO, 2021). While some people with HIV may go on to develop HIV-associated neurocognitive disorders (Cysique & Brew, 2019), the course of dementia typically involves gradual cognitive decline despite supportive interventions (WHO, 2021). Nonetheless, the role of PAC in both contexts converges around supporting emotional resilience, promoting agency, and reducing stigma. In dementia care, PAC may not alter the clinical trajectory of the condition, but it can enable individuals and families to reframe the diagnosis as a new phase of life where proactive planning, psychosocial support and adapted routines can still enable connection, meaning, and dignity. As the HIV example demonstrates, early and compassionate communication can reshape both personal and societal narratives, mitigating fear and encouraging adaptive responses to life-altering diagnoses.

Autism Assessment.

PAC within autism assessment is typically directed toward parents or carers and serves to reduce diagnostic uncertainty, correct misconceptions, and provide clarity on support services (Bendick & Spicer-White, 2021). The structure of these sessions is often geared towards enabling families to make informed decisions about education, interventions and long-term care. The diagnostic process for autism usually occurs during childhood or adolescence, and PAC is embedded in a framework that includes developmental planning and multi-agency support (Bendick & Spicer-White, 2021). In dementia, however, the diagnostic audience is often the individual themselves, potentially accompanied by an adult child or their spouse. The emotional and cognitive readiness of the person with suspected dementia varies considerably. In addition, the progressive nature of dementia and its impact on autonomy mean that discussions about future care, legal planning and emotional adjustment should be prioritised. These contrasting clinical and relational contexts highlight the need for dementia-specific adaptations to PAC content, structure, and timing. Drawing from these established PAC models, it becomes evident that PAC in dementia care may offer comparable support in managing emotional, practical, and social challenges. Unlike post-diagnostic counselling, which offers support after a formal diagnosis (Cheston & Ivanecka, 2017), PAC provides anticipatory guidance and emotional support at an earlier stage, prior to formal testing or diagnosis. La Fontaine et al. (2014) explain that the purpose of PAC as an early intervention within dementia care should aim to reduce anxiety, manage the expectations of both the person with suspected dementia and the family members that they have brought with them by enabling a clear understanding of the potential implications of a diagnosis. It should also provide the opportunity for them to ask questions both about dementia and the process of diagnosis, as well as engage in conversations concerning future planning with the aim of being able to make considerably more informed decisions.

PAC in dementia care emerged as a response to the need for additional support and education prior to formal assessment (La Fontaine et al., 2014), drawing inspiration from pre-diagnostic counselling in other areas, such as HIV services. Although its implementation is unique to certain NHS Trusts and lacks a universal framework, PAC is viewed as a promising approach to improve diagnostic experiences and outcomes. PAC provides an opportunity to address the challenges experienced within cognitive, social and emotional areas of a person who is undergoing a dementia journey in the early stages.

In doing so, PAC can help to reduce some of the initial psychological distress of people experiencing cognitive decline as it aims to provide them with a more comprehensive understanding of what dementia is and what it is not and discuss coping mechanisms that have previously been employed (La Fontaine et al., 2014) prior to diagnosis, aligning with the biopsychosocial approach mentioned previously, enabling a more holistic approach to the management and understanding of dementia. Where PAC is implemented within dementia care pathways, it is typically delivered by specialist healthcare professionals within memory assessment services (La Fontaine et al., 2014). These appointments are held either within the memory clinic or at home and offer individualised care and support to the person experiencing cognitive decline and those whom they choose to be present, which is typically a spouse or child (La Fontaine et al., 2014).

As already mentioned, carers play a critical role in the well-being of people who live with dementia and in recognition of this, PAC aims to support carers with knowledge and skill provision to enable confidence in supporting the person they care for effectively (Lecouturier et al., 2008). PAC assists carers in navigating a new role through the delivery of individualised guidance that addresses both their practical and emotional needs to reduce the stresses and strains of the role and ultimately improve their experience of caring for a person with dementia (Lecouturier et al., 2008). PAC in dementia care includes information provision on dementia, potential treatment options available, as well as psychosocial support that aims to encourage people experiencing cognitive decline to make informed decisions concerning how they wish to progress with their dementia journey (La Fontaine et al., 2014). By addressing complex dementia risk factors and supporting person-centred care, PAC promotes holistic and equitable dementia care, which aligns well with the social determinants of health perspectives to improve outcomes for people with dementia and their carers.

Receiving a dementia diagnosis can be a profoundly destabilising experience, often accompanied by fear, grief, and a sense of psychological dislocation. It marks the beginning of a progressive loss of memory, independence, and selfhood, and can be experienced as a form of social and existential rupture (Derksen et al., 2006; Jetten et al., 2010). PAC is not simply an opportunity to offer information but a critical intervention designed to support people in confronting a life-changing diagnosis that threatens their autonomy and identity. By providing timely, tailored support, PAC helps individuals and families begin to process this transition, not only by increasing understanding, but by validating emotional responses and restoring some degree of control during a highly vulnerable moment (La Fontaine et al., 2014). Essentially, PAC seeks to provide people living with dementia and those who care for them with all the necessary information, guidance and support that is relevant to them and will enable them to psychologically prepare for the diagnostic journey and the outcomes (La Fontaine et al., 2014). By being able to discuss care preferences and concerns, people with dementia can share any misconceptions that they might have and be reassured throughout the process (Hadley et al., 2019). As QoL is a critical objective within the dementia care pathway, PAC enables this through its aim of supporting people with dementia to feel in control and to retain both their dignity and agency prior to receiving a diagnosis. Therefore, by engaging people with dementia and their families in conversation topics such as future planning and potential treatment options, PAC enables momentary well-being but also continues to maintain QoL.

Therefore, PAC exemplifies a person-centred approach that empowers people with dementia to actively participate in decision-making about their future care, reinforcing personal fulfilment and autonomy (Smebye et al., 2012). (A more nuanced description of PAC can be found in the qualitative interviews conducted with healthcare professionals in Chapter 4.)

As PAC is not a service widely embedded within dementia care pathways, it continues to develop as an intervention. A number of psychological and communication theories are compatible with PAC's person-centred approach and support its effectiveness in meeting the cognitive, social, and emotional needs of people with dementia and their carers. In this way, these theories make PAC a framework that can assist in delivering care tailored to the specific requirements of people with dementia and those who look after them. Although PAC has been noted to be employed within other healthcare pathways such as genetic counselling, oncology, HIV care and autism assessment (Bendick & Spicer-White, 2021; Cheston et al., 2000; Mega et al., 2020; Williams, 2004), it remains to be largely absent in dementia care. It is possible that this may be due to the view of dementia being a condition for which there are few treatment options and a focus on palliative care (Eisenmann et al., 2020). This inequality indicates that there is the prospect of addressing the unmet needs of people living with dementia and those who care for them within the dementia care pathway, as they also encounter similar psychological challenges to those healthcare pathways where PAC is routinely used.

This thesis will explore and analyse why PAC has not been fully integrated into dementia care as it has been in other areas of healthcare despite the challenging psychological parallels that people with dementia endure on their diagnosis journey. By placing PAC within the dementia care pathway, this thesis endeavours to bridge a significant gap within the field, addressing the presently unmet practical and emotional needs of people living with dementia.

The prevalence of dementia places increasing demands on healthcare systems that require continue evolution to meet the needs of people with dementia and their families as numbers continue to rise globally (Livingston et al., 2020). PAC offers a proactive approach in the form of anticipatory support that could improve experiences of the diagnostic journey for people living with dementia, which highlight the potential contributions that this thesis endeavours to advance theoretical person-centred care and clinical practice. This timely exploration of determining the role that PAC may have in the dementia care pathway means that it could help to shape and improve care provision and policies and, as such, the theoretical foundations upon which PAC is built require further examination to provide a comprehensive understanding as to its full potential.

Theories Incorporated in PAC

The application of PAC within dementia care is limited despite its integration into other healthcare pathways. Historically, dementia care has tended to lack preparatory stages, which may be a reflection of the differences between the social views of dementia and the progression of the condition (Nimmons et al., 2023). A closer investigation is required to understand why this intervention is lacking in dementia care despite the equivalent psychological challenges and highlights the potential impact of this thesis. PAC in dementia care is built on theoretical foundations that reinforce its purpose, which is to provide a compassionate, person-centred approach to the diagnostic journey. Person-centred care is at the core of PAC, ensuring that each individual's unique needs, values, and preferences are respected, with an emphasis on early and timely diagnosis as central to effective support (Kitwood, 1997; La Fontaine et al., 2014). Chapter 4 investigates this fundamental approach to care and highlights the significance of placing people with dementia at the centre of their diagnosis journey through the application of holistic personalised care that respects their well-being and autonomy. Chapter 2 highlights this further by demonstrating how PAC enables the psychological adjustment of people with dementia and improves the quality of diagnosis disclosure by healthcare professionals. Chapter 3 further contributes to this understanding by demonstrating that PAC's emphasis on timely diagnosis reduces fear and anxiety for people with dementia and their families.

To further strengthen the person-centred focus of PAC, Communication Accommodation Theory (CAT; Giles & Ogay, 2007) guides healthcare professionals in adapting their communication to meet the cognitive and emotional needs of carers, as discussed in Chapter 2, and also for people with dementia as noted in Chapter 4. The systematic review in Chapter 2 highlights PAC's impact on enhancing information clarity and diagnosis disclosure quality, which CAT supports by ensuring that communication is tailored and accessible (Giles & Ogay, 2007). Chapter 4 demonstrates how adjusting communication styles fosters trust, reduces anxiety, and enhances engagement, creating a supportive environment for processing complex diagnostic information (Momand et al., 2022). By making information accessible and empathetic, PAC helps people with dementia and carers feel heard and understood, which is essential for building trust and facilitating informed decision-making (Chan et al., 2024).

Self-Determination Theory (SDT; Deci & Ryan, 2012) deepens PAC's emphasis on autonomy, addressing the fears that can accompany a potential dementia diagnosis. PAC provides a safe space where people with dementia are encouraged and supported to make decisions about their diagnosis journey, where emotional resilience and autonomy are reinforced (Tang et al., 2017). Chapter 5 builds on this, where results show that PAC reduces stress for people with suspected cognitive decline prior to undergoing an assessment for dementia. This chapter's findings reinforce the principles of SDT by demonstrating that when individuals feel in control of their healthcare decisions, their overall well-being improves (Keelson et al., 2024). Thus, PAC's alignment with SDT is critical for empowering people with dementia and reducing the psychological impact of diagnosis.

For those in the early stages of cognitive change, PAC's approach to the assimilation of problematic voices model (Stiles, 2001) helps people with dementia and carers move from denial or explaining away concerns to acknowledging cognitive changes. This progression, facilitated by PAC, allows people with dementia to engage constructively with a potential diagnosis by understanding and developing strategies for managing the emotional impact of cognitive change (Stiles, 2001), further reinforcing PAC's person-centred approach. Chapter 4 elaborates on this in more detail. Healthcare professionals use PAC to support people with dementia and their carers in the early stages of the dementia diagnosis journey so that they can identify and accept cognitive changes. This demonstrates how PAC can increase understanding and resilience where people with dementia can be supported to accept their signs of cognitive decline through a person-centred approach to care.

The Family Systems Illness Model (FSIM; Rolland, 1994) strengthens PAC's relevance to family members of people with dementia, which addresses how chronic illness can impact family dynamics and how it adapts to a diagnosis. PAC assists those who care for someone with dementia to understand how it could affect their relationships and develop coping strategies and resilience to manage the challenges that can come with a diagnosis during the pre-assessment stage, and this is discussed further in Chapters 2 and 6. This is further supported by the systematic review in Chapter 2, which highlights the importance of consistent practices that build family resilience and identifies the role that PAC plays in providing vital support for carers. Chapter 6 demonstrates how PAC can assist carers in navigating the emotional and informational demands of a dementia diagnosis, highlighting the positive impact that PAC has on carers' experiences and well-being.

The theoretical grounding for this thesis primarily draws on the Stress and Coping Theory (SCT; Lazarus & Folkman, 1984) and Kitwood's Person-Centred Care framework (1997). SCT conceptualises diagnosis as a stressor that individuals cognitively appraise and emotionally respond to, with coping shaped by available support and perceived control. This model is especially relevant to PAC in dementia because it acknowledges the affective and anticipatory burden associated with seeking a diagnosis for a progressive condition. However, the model has been critiqued for underemphasising social and relational dynamics, which are central to dementia experiences. Kitwood's framework addresses this by foregrounding personhood, relational care, and the psychosocial dimensions of cognitive decline (Kralik et al., 2006; Hydén, 2011). Although often applied post-diagnosis, this model provides a robust foundation for framing PAC as a relational and rights-based intervention. Alternative models, such as Shared Decision-Making (Charles et al., 1997), offer valuable insights into collaborative care but assume a more stable cognitive baseline and clear decision points, which may not be appropriate in dementia contexts. By combining a stress-appraisal perspective with a personhood-based approach, this thesis adopts a theoretical stance that reflects both the emotional weight and identity disruption associated with pre-diagnostic stages of dementia.

Summary

By critically examining the gaps in dementia care and the potential role of PAC, this introduction frames the thesis' core argument: that PAC represents an underutilised but essential strategy for improving diagnostic experiences, emotional resilience, and care outcomes in dementia services. This will be the cornerstone for supporting the programme of studies undertaken within this PhD, where the goal is to identify the practical and emotional benefits of PAC for people living with dementia and their families, as well as determining the possibility for it to be included more widely within dementia care frameworks. This introductory chapter has also explored dementia care and has contextualised it within the wider landscape of psychology and healthcare. Furthermore, it investigated the physical, cognitive, social and emotional facets of dementia by drawing upon a number of theoretical perspectives from clinical, cognitive, social and health psychology fields to develop a holistic understanding of dementia and its impact upon those who live with the condition and those whose role it is to care for them. Furthermore, as dementia prevalence increases globally, services face continued challenges to provide care that meets the needs of people with dementia and their carers (Livingston et al., 2020). By promoting early diagnosis and enabling understanding as to its importance means that people with dementia can access interventions that help them and those who care for them manage the condition at the earliest stages of the dementia care pathway. This comprehensive care, tailored to the needs and requirements of people living with dementia and their families, is delivered through memory assessment services, specialist clinics and post-diagnostic support initiatives.

By recognising the difficulties that people experiencing cognitive decline say that come with a diagnosis of dementia, PAC emerges as a crucial intervention within the dementia care pathway. This is because PAC provides individualised, tailored support and guidance to people living with dementia to empower them to make decisions that enable them to navigate the dementia diagnosis journey with increased understanding and resilience (La Fontaine et al., 2014). PAC’s rationale is based on its ability to seemingly meet the emotional, informational, and decision-making needs of people considering assessment for dementia. By reducing stress and enhancing coping strategies, PAC seeks to enable people with dementia to engage with their journey to diagnosis in a meaningful way, where they are provided with a platform to discuss symptoms, procedures, treatment options and psychosocial support (La Fontaine et al., 2014). As PAC has been introduced within other healthcare pathways where service users receive life-changing diagnoses, this success across multiple care services highlights the flexibility of PAC. It supports its use in dementia care, where there is an equally significant demand for anticipatory support.

The highlighted gaps in dementia care pathways and sparse use of PAC in this area, raise a number of research questions that this thesis aims to address which include: (1) How does PAC impact psychological well-being and diagnostic readiness in people with dementia? (Addressed in Chapters 3 and 5.) (2) How does PAC affect carer preparedness and coping strategies pre-diagnosis? (Addressed in Chapters 2, 4 and 6.) and (3) Can PAC reduce the barriers to timely dementia diagnoses, and if so, how? (Addressed in Chapters 2, 3 and 4.) These questions are explored through both quantitative and qualitative methods to capture PAC's comprehensive impact. The central hypothesis posits that PAC will significantly enhance both the emotional resilience of people with dementia and the coping capacity of carers, fostering a more person-centred approach within the dementia diagnostic process.

Chapter 2: The Role of Pre-Assessment Counselling in Dementia Care: A Systematic Review of Its Impact on People with Dementia, Carers and Healthcare Professionals

It is well-documented that both people with dementia and their carers face emotional and practical burdens during the diagnostic process (Clare et al., 2014; Koch & Iliffe, 2010), these studies often overlook how the structure and timing of diagnostic support—such as PAC—might either mitigate or exacerbate these challenges. A dementia diagnosis has distinct consequences in contrast to other diagnostic processes as it impacts upon identity, relationships and autonomy in addition to affecting cognitive health (Bryden, 2020, Orgeta et al., 2022; Wolfe et al., 2021). Pre-assessment counselling (PAC), which addresses the multifaceted effects of a dementia diagnosis at an early stage, has the potential to be a beneficial intervention to assist people with dementia and their carers in navigating this challenging journey (La Fontaine et al., 2014). Although PAC is suggested to reduce anxiety around dementia assessments through information, guidance, and emotional support (La Fontaine et al., 2014), empirical evaluation of these specific mechanisms remains limited, highlighting the need for further research into how and for whom PAC achieves these effects. However, despite preliminary endorsements of PAC's potential, its empirical evaluation remains sparse, particularly regarding how effectively it prepares individuals for the cognitive assessments central to dementia diagnosis—a critical gap this review seeks to address.This chapter consists of a systematic review that was undertaken to determine if PAC is an intervention that is considered beneficial and necessary within the dementia care pathway for people experiencing cognitive decline and synthesises the empirical evidence concerning PAC in dementia care.

Agency and the right to choose are foundational principles in person-centred healthcare (Entwistle & Watt, 2013). For people living with dementia, this principle becomes even more urgent given the progressive nature of the condition and the anticipated decline in cognitive and decision-making capacity over time. Unlike many other mental health diagnoses, dementia presents a unique existential challenge in that individuals are often aware that they may eventually lose key aspects of their identity, memory, and sense of self (Sabat & Harre, 1992; Beard, 2004). This awareness can invoke fear, uncertainty, and emotional ambivalence about seeking a diagnosis. PAC aims to support timely, informed decision-making about whether and when to pursue diagnosis; however, whether such decisions are consistently facilitated or even feasible for all individuals remains under-explored and warrants closer scrutiny. Offering more than just information, it engages people in a reflective process that respects their autonomy, acknowledges their psychological readiness and promotes self-determination. By enabling individuals consider how a diagnosis may intersect with their sense of identity and future self, PAC can mitigate distress and empower people to shape their diagnostic journey in ways that align with their values and emotional needs.

As dementia is recognised as being a serious public health issue (WHO, 2021), it is necessary to undertake a systematic literature review exploring the implementation of PAC in dementia care pathways. The degenerative nature of the condition means that not only will the person living with dementia experience a myriad of challenges but so too will those who care for them as they step into the role of becoming a carer, dealing with the physical and emotional difficulties of care provision (Kovaleva et al., 2018; Orgeta et al., 2022). Additionally, healthcare professionals may find it difficult to enable autonomy for a person with dementia and support the needs of family members whilst diagnosing dementia sensitively. Therefore, healthcare professionals may also benefit from a structured approach at the beginning of the diagnosis journey to help manage expectations and assist readiness for a potential diagnosis of dementia. However, while other healthcare domains have established PAC as a standardised intervention including genetic counselling (Mega et al., 2020), oncology (Cheston et al., 2000), HIV care (Williams, 2004), and autism assessment (Bendick & Spicer-White, 2021), PAC in dementia care remains relatively unstructured and lacks comprehensive evaluation. The approach to how PAC is formatted and what it should contain may need to be adapted within the dementia care pathway as so to meet the needs of all within the triadic relationship of the person with dementia, carer and healthcare professional, leaving unanswered questions in the absence of a comprehensive review of literature. These gaps demonstrate why a systematic review is required. By systematically evaluating the literature, this review contributes to the development of an empirically grounded understanding of PAC's potential role as an early intervention in dementia diagnosis, while also identifying the assumptions and limitations embedded in current approaches.

Systematic literature reviews can inform clinical practice and future research as they follow a structured, replicable format and robust appraisal (Mallett et al., 2012). While systematic reviews offer a structured and potentially rigorous foundation for practice, their validity and reliability are contingent on the methodological robustness of the studies they synthesise—an important consideration given the limited and heterogeneous nature of the

PAC literature. A systematic review enables a rigorous, evidence-based assessment of the value of PAC by synthesising its use within dementia care, examining its effectiveness, and highlighting key areas for development. This review specifically seeks to ascertain whether PAC facilitates psychological adjustment for people with dementia, fosters comprehension and acceptance of the diagnostic process, and improves communication and relationships among people with dementia, carers, and healthcare professionals. Additionally, carrying out this review using a structured approach makes it possible to compare the use of PAC in dementia care with well-established best practices from other healthcare domains, where PAC has been personalised to meet the unique needs of people with dementia. These interdisciplinary findings might highlight crucial tactics and best practices that should be modified to help people navigating the dementia diagnosis journey.

This PhD begins with a systematic review in order to establish a clear evidence-based foundation for the empirical work that follows. Although other methodologies such as narrative and scoping reviews were considered, they were less well-aligned with the aims of this research. Narrative reviews can offer broad context but often lack the rigour and transparency required for replicability and bias reduction (Fitzgerald & Rumrill, 2005). Scoping reviews are suited to mapping emerging fields but typically prioritise breadth over critical appraisal, limiting their value for synthesising evidence in depth (Mak & Thomas, 2022). A systematic review was therefore selected for its capacity to critically analyse and appraise existing research using transparent methods, supporting the identification of conceptual and methodological gaps that informed subsequent study design (Mallett et al., 2012). The limited number and variable quality of included studies are acknowledged and addressed in the discussion.

Additionally, this review aims not only to explore the application of PAC within the dementia care pathway but also to determine if it should be considered a critical element of the diagnosis journey. PAC is already employed in other healthcare pathways previously mentioned to prepare people with dementia and their families for life-changing diagnoses. However, its implementation is limited within dementia care. Literature has discussed that PAC aids autonomy for service users, reduces emotional distress and improves familial support (La Fontaine et al., 2014). However, the potential for these outcomes to be beneficial in dementia care is largely yet to be verified. Without such a review, dementia care would lack a coherent understanding of PAC's role and potential in mitigating the psychological, social, and relational challenges that uniquely accompany dementia diagnoses.

This systematic review thus aims to critically appraise the evidence and existing literature regarding PAC for dementia, primarily focusing on its provision, as well as its benefits and usefulness to people with dementia, their carers, and healthcare professionals. Given that PAC remains underutilised in dementia care, this review will examine whether implementing PAC as a standardised part of the dementia diagnostic process could address some of the unique psychological and relational challenges associated with receiving a diagnosis. This review attempts to find areas for development and best practices in PAC delivery by assessing and synthesising the current data, which may inform clinical practice and policy. It is anticipated that the insights obtained through this comprehensive approach will help guide suggestions for improving the integration of PAC into dementia services and creating a more inclusive and patient-centred diagnostic pathway.

Method

Design

This review is written from a realist ontological standpoint. This means that the themes are considered to be representative of patterns that are observable and consistent within empirical literature as opposed to that which is formed according to the interpretation of the researcher (Jenkins, 2010). Therefore, the most appropriate method to synthesise the data for this review was considered to be thematic analysis for a number of reasons. Firstly, there were only a very small number of empirical studies that were eligible to be included within the review and despite this, the methodologies were varied ranging including quantitative, qualitative and mixed-methods designs. Thematic analysis can meet this diversity owing to its highly flexible approach meaning that broad themes are able to be identified across different types of data (Braun & Clarke, 2006). Thematic analysis is more appropriate than other synthesis methods such as meta-ethnography or meta-analysis as these require homogeneity across the data. Furthermore, thematic analysis is especially suited for pinpointing major themes that reveal significant patterns across various studies without the need for extensive prior investigations (Braun & Clarke, 2006), which is in line with the goal of gaining a preliminary understanding of PAC in the relatively unexamined area of dementia care. In contrast to other synthesis techniques, such as framework synthesis or critical interpretive synthesis, thematic analysis enables both descriptive and interpretative synthesis (Braun & Clarke, 2006), promoting a detailed yet comprehensive understanding of the function of PAC in dementia care. One possible drawback of thematic analysis, even within a realist perspective, is its dependence on the researcher's interpretation when recognising and defining themes. This can lead to a degree of subjectivity, as the judgment of the researcher is involved in determining which themes most accurately represent the data (Braun & Clarke, 2006). Nonetheless, the realist approach guiding this review aimed to reduce interpretive bias by focusing on the consistency of theme identification across studies. By anchoring themes in patterns that consistently emerged across the chosen studies, this method sought to portray objective findings rather than interpretations that are overly shaped by the viewpoints of the researcher.

Each of the included studies was summarised following having been read fully. The data used within this analysis included any information extracted from the papers that could be interpreted as a finding or a conclusion that was relevant to the research question. The initial codes were generated from the data at a semantic level and then organised into descriptive themes which were obtained inductively. All stages of the review, including title and abstract screening, full-text review, data extraction, and quality appraisal, were primarily conducted by the author. While dual-reviewer processes are considered best practice to minimise bias (Higgins et al., 2022), the single-author nature of this PhD necessitated this approach. To enhance transparency and replicability, the review followed a pre-specified protocol with clearly defined inclusion and exclusion criteria, and all decisions were documented using a PRISMA flow diagram. A data extraction form was developed and applied consistently, and methodological quality was appraised using the CASP, MMAT and EHCCP tools ensuring a structured approach to evaluating the evidence. A second reviewer was not available to independently verify screening and extraction, which may introduce bias. However, consistency in the application of criteria and transparent documentation were used to mitigate this.

Each of the included studies was read in full, and a structured summary was created for each, capturing relevant findings, conclusions, and contextual factors linked to the research question. Extracted data, whether directly quoted or paraphrased, were selected to maximise transparency and ensure a faithful representation of authorial intent, enabling consistent and reliable cross-study comparisons. By coding at a semantic level, the review prioritised manifest content across studies, facilitating the identification of consistently reported features of PAC and minimising interpretive bias during early coding stages. Coding was performed manually in Excel, and descriptive themes were developed from these codes.

The research team subsequently reviewed and refined the themes collaboratively by re-examining the coded extracts to ensure consistency and coherence.

Search Strategy

The search strategy used in this systematic review followed PRISMA guidelines (Page et al., 2021), focusing on peer-reviewed articles indexed in major databases. Five databases were used to search for the literature used within this systematic review. PubMed was used as it provides free access to one of the largest searchable biomedical databases. PsycInfo was included as it is one of the most frequently used online psychological search services offering extensive access to articles. Science Direct was also used as it delivers uncompromised access to full-text articles coupled with its ability to make targeted recommendations on suggested articles. Scopus was included as it is the largest abstract and citation database of peer-reviewed literature in scientific journals. Web of Science was included as it is possible to follow a trail of cited and cited papers to find relevant literature efficiently.

To identify potentially appropriate articles, the following search terms were used: ‘pre-assessment counselling’ AND ‘dementia’, ‘pre-diagnostic counselling’ AND ‘dementia’, and ‘pre-diagnosis’ AND ‘dementia’ to ensure that any alternative names for pre-assessment counselling were captured as terminology within the literature may differ. Furthermore, using the search terms ‘pre-diagnosis’ and ‘dementia’ meant that any empirical studies that evaluated or described interventions that are used within the dementia diagnosis journey could be captured as these might provide a form of readiness or educational support. In this way, a comprehensive search by using as many variations in terminology as possible was undertaken. However, this review chose to exclude grey literature and non-English language studies. This was to ensure the quality of peer-reviewed studies and to enable high methodological rigour (Hartling et al., 2017). Furthermore, it was considered necessary for non-English language papers, in particular owing to constraints of resources and the possible challenges that accompany accurate translation and interpretation of results, which had the potential to introduce bias.

Inclusion and Exclusion Criteria

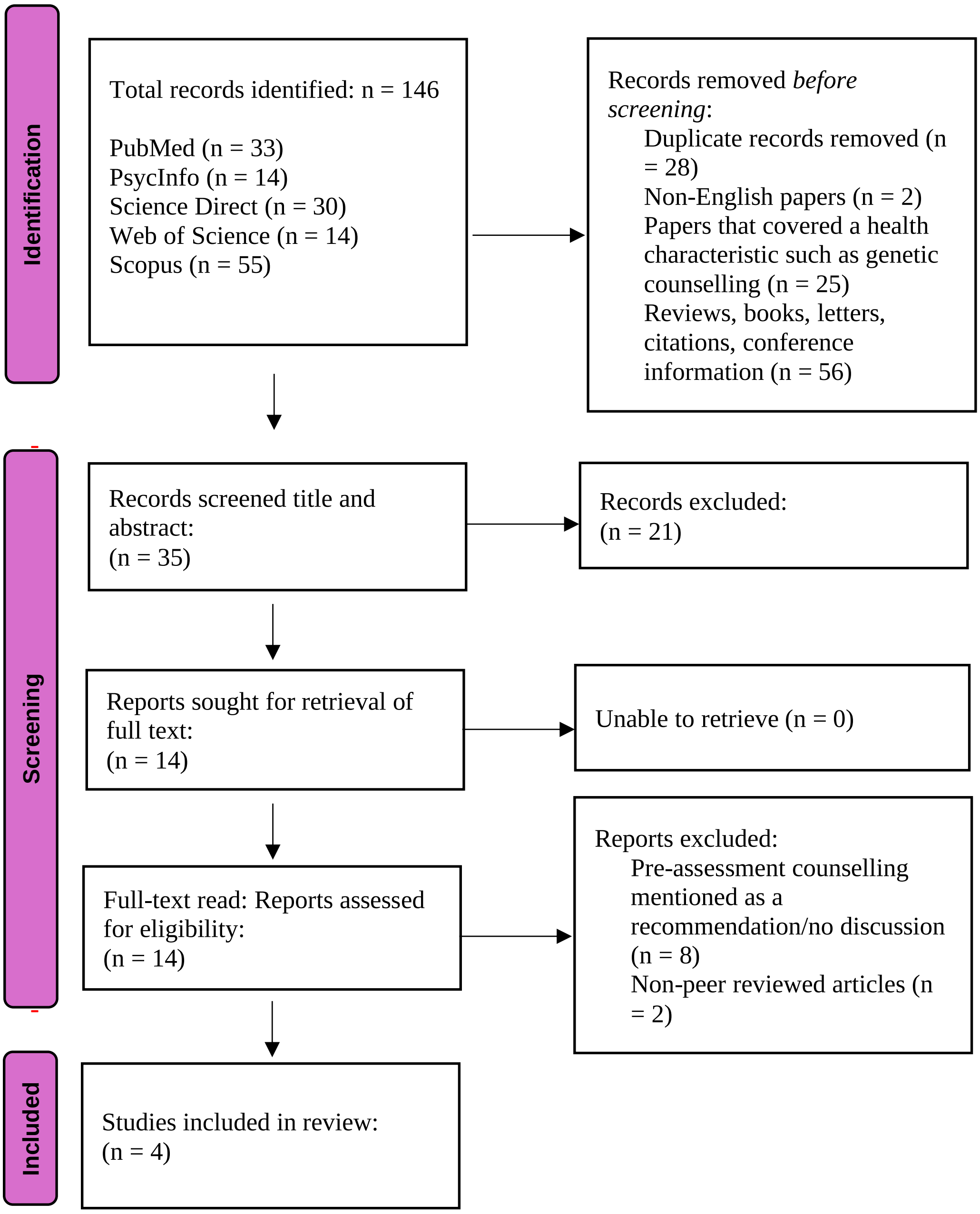
Studies that included participants with dementia and those suspected to have dementia, as well as carers who had received PAC and healthcare professionals who had delivered PAC, were included. Exclusion criteria included post-diagnostic counselling with people with dementia, carers and healthcare professionals. Additionally, articles with specific health characteristics, such as genetic counselling for dementia, were also excluded. This was because biomarker counselling involves pre- and post-sampling discussions regarding the ability to predict the risk of mild cognitive impairment progression as well as the ability to diagnose the underlying pathology/disease. Further to this, most people who receive a diagnosis of dementia do not undergo genetic counselling first (Dementia UK, 2023). Non-English papers were excluded and removed as well as duplicated studies when encountered. Publications that were not peer-reviewed and did not use empirical data, such as reviews, books and book chapters, were excluded. This was because searching for conference abstracts, for example, is resource intensive and may need more adequate information and reviews, and editorials are commonly excluded in systematic literature reviews (Scherer & Saldanha, 2019).

Article Selection

The search strategy followed PRISMA guidelines (Page et al., 2021), using the terms detailed above in the Search Strategy section across five databases. No date range constrained the search results. This yielded 146 articles screened for relevance and eligibility based on predefined inclusion and exclusion criteria. Figure 1 shows a flow diagram of the selection process.

Figure 1

PRISMA flow diagram of the study selection process (Page et al., 2021)



Quality Assessment of Included Studies

The Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme, 2018) was used to assess the quality of the qualitative article included within this review where discernment is required to assess whether the study met the ten questions on quality posed. The Mixed Methods Appraisal Tool (MMAT) was used to assess the quality of the mixed methods study (Hong et al., 2018) to evaluate if the mixed methods study met the 25 questions set to determine quality. The quantitative studies were assessed for quality using the Effective Public Healthcare Panacea Project (EPHPP) tool (2009) in this review and are scored differently where '1' is 'strong', '2' is 'moderate' and '3' is 'weak'. To assess the overall quality of each study, this review used the National Institute for Health and Clinical Excellence (NICE, 2007) checklists, as they explicitly relate to healthcare-related studies (see Table 1). These checklists were used to accompany the former quality appraisal tools as its use was not limited by the methodology used in each study and provided a standardised system for scoring where studies scored as ++ have most criteria satisfied, studied scores as + have some criteria satisfied, and – when few or no criteria have been satisfied.

Table 1 shows the criteria for each of the appraisal tools implemented. In two papers, most of the NICE (2007) criteria were satisfied (Jha et al., 2012; Rubinsztein et al., 2015), and for the other two, some of the NICE (2007) criteria were satisfied (Lecouturier et al., 2008; O'Malley et al., 2020). This meant that the quality of all the studies was sufficient in providing meaningful evidence to support this review, but most importantly, it pointed to how future research can be methodologically improved. Table 2 shows how the studies were scored in line with the appropriate appraisal tools.

Results

Study Characteristics

Of the four studies included in this systematic review, one explored the direct impact of PAC upon its findings and three evaluated the usefulness of PAC. Two studies sought people with dementia as participants, one study sought people with dementia and carers as participants, and one study sought clinicians who worked in dementia care as participants. The oldest paper was published in 2007 (Lecouturier et al., 2008), and the newest paper was published in 2020 (O'Malley et al., 2020). Out of the four papers which met the criteria for

Table 2

Studies of Pre-Assessment Counselling in Dementia Care

Author(s), Year	Country that the study was conducted in	Aims	Recruitment & Participants	Methodology/Data collection	Main findings	Limitations	Criteria Met Appraisal Score	NICE quality score
Jha et al., 2012	UK	To explore whether recovery-oriented psychiatric assessment and therapeutic intervention can improve the well-being of individuals with dementia and their family carers	34 people with dementia equally split between control and 'recovery' groups. Recovery participants received PAC and well-being assessments, diagnostic consultation and post-diagnostic support for 6 months using the WHO Wellbeing Index as the primary measure.	RCT. Quantitative	Participants in the "recovery" group demonstrated notable improvements in the WHO Well-Being Index, alongside trends suggesting enhancements in other outcomes.	A relatively small sample size, compounded by participant dropouts over the 6-month study period, limited the study's generalisability. Additionally, participants in the recovery group were aware they were receiving a new psychosocial intervention, potentially influencing their responses and outcomes positively.	EPHPP overall score: 1	++
Lecouturier et al., 2008	UK	To identify key disclosure behaviours and assess whether integrating alternative methods alongside a literature review could reveal additional behaviours.	4 people with dementia, 6 carers, 8 healthcare professionals.	Qualitative interviews. Content analysis of the full list of behaviours was carried out.	Disclosure behaviours were categorised into eight themes: preparation for disclosure (including pre-diagnostic counselling); involving family members; understanding the patient's perspective; delivering the diagnosis; addressing patient reactions; prioritising quality of life and well-being; future planning; and effective communication.	Recruitment challenges resulted in only 4 interviews with individuals living with dementia and 6 with carers. The structured approach may have constrained the panel members' responses, emphasising behaviours they deemed most important rather than capturing a broader spectrum of behaviours. Empirical evidence is limited regarding the routine implementation of these behaviours and their impact on delivering sensitive information.	CASP: 6 out of 10 points satisfied	+

O’Malley et al., 2020	UK	To develop clinician-focused guidance on critical elements that support decision-making during the diagnostic evaluation of young-onset dementia.	23 healthcare professionals	Mixed Methods Research	A consensus of 80% was reached on 48 statements deemed “absolutely essential” or “very important” for conducting a comprehensive assessment of dementia in younger adults. Pre-assessment counselling, ensuring all participants understood potential outcomes (including the possibility of receiving a diagnosis), was considered crucial by 100% of experts. The expert panel maintained a high response rate across three rounds (91.3%).	The panel lacked representation from allied health professionals, such as occupational therapists and speech and language therapists, which may have influenced the results.	MMAT: 14 out of 25 points satisfied	+
Rubinsztein et al., 2015	UK	To compare the cost-effectiveness and quality of care provided by a memory-clinic-based service (MCS) with that of a traditional community mental health team (CMHT) model.	66 people with dementia	Quantitative	The MCS model was less expensive than the CMHT model, although the cost difference was not statistically significant. However, the MCS provided more comprehensive and multidisciplinary care, including pre- and post-diagnostic counselling, screening, and guidance. This demonstrates that memory-clinic-based services can deliver enhanced care without additional costs to secondary care.	Ethnic diversity was not a focus of this study, and the small sample size further limited the findings. Variability in clinician perspectives on what constitutes a high-quality memory service remains a consideration.	EPHPP overall score: 1	++

Note: PAC (pre-assessment counselling), WHO (World Health Organisation), RCT (randomised controlled trial), MCS (memory clinic services), CMHT (community mental health team) inclusion in this review, two included an evaluation of PAC in dementia care (Jha et al., 2012, and Rubinsztein et al., 2015), and the remaining two discussed the requirement of PAC as an essential component of dementia care (Lecouturier et al., 2008, and O'Malley et al., 2020). Concerning the methodology of these studies, two employed quantitative methods (Jha et al., 2012, and Rubinsztein et al., 2015), one utilised qualitative methods (Lecouturier et al., 2008) and one used a mixed-methods design (O'Malley et al., 2020). Participant numbers varied, likely due to the method used to approach the research, with the smallest including 18 participants (Lecouturier et al., 2008) and the largest recruiting 66 participants (Rubinsztein et al., 2015). A summary of all the studies included in this review can be found in Table 2.

Given the heterogeneity in study design and participant types, one analytical challenge involved synthesising diverse data sources while maintaining consistency across themes. Given the heterogeneity of the included studies which varied in their stakeholder focus, aims, and delivery models, findings were not statistically pooled but instead analysed thematically. Though this diversity limits direct comparison it does provide valuable insight into the fragmented and inconsistent development of PAC in dementia care. Rather than weakening the review, these methodological differences were used as a critical lens to identify gaps in the literature, including the absence of standardised PAC guidelines, limited involvement of key stakeholders, and variation in materials and intended outcomes. These gaps reinforce the rationale for the empirical components of this thesis, which aim to build a more cohesive understanding of how PAC is delivered, perceived, and experienced in practice.

A thematic synthesis approach was used to analyse the included studies following the methodology outlined by Thomas and Harden (2008). This involved line-by-line coding of the findings sections of each paper using NVivo software, with codes developed inductively and iteratively across studies. These codes were then grouped into descriptive themes, which were refined into higher-order analytical themes through continual re-reading of the data. This process was grounded in systematic data handling with analytic decisions documented throughout. Although the synthesis was conducted by a single researcher, efforts were made to enhance transparency and consistency by applying the same extraction and coding framework across all studies. The themes presented were intended as evidence-informed insights into how PAC is conceptualised, delivered, and experienced, and to identify gaps that informed the empirical stages of the thesis.

Although studies consistently report benefits of PAC for service provision and diagnosis delivery, these findings may be shaped by positive reporting bias or limited critical engagement with negative outcomes, warranting cautious interpretation. However, there is a risk of inclusion bias, as participants in several studies were already positively disposed towards PAC either due to prior exposure, voluntary participation or professional alignment with person-centred approaches. This may have skewed the findings toward more favourable evaluations of PAC, limiting the generalisability of conclusions.

As this systematic review aimed to evaluate whether PAC is necessary within the preliminary stages of a person's dementia journey to diagnosis, common points across the literature were noted, enabling themes to be generated. These included its usefulness to all individuals who might be impacted through its provision, including people with dementia, supporting these populations. With these in mind, this systematic review identified 3 themes. (1) PAC enables psychological adjustment of a person with dementia to a potential diagnosis, (2) PAC provision supports healthcare professionals with quality diagnosis disclosure, and (3) PAC brings family members into discussions to assist them in supporting their loved one. No subthemes were noted for any of these themes.

Pre-Assessment Counselling Enables Psychological Adjustment of a Person with Dementia to a Potential Diagnosis

Studies noted the value of PAC in assisting psychological adjustment to diagnosis for people with dementia. According to Lecouturier et al. (2008), some people with dementia and their families might anticipate a diagnosis. However, others had not formally perceived dementia as a potential reason for cognitive issues, and as such, for these people without having received PAC, the diagnosis might come as a shock. They also indicated that by advising people of the potential for a diagnosis of dementia, levels of anxiety following the disclosure of a formal diagnosis are reduced. The study by Jha et al. (2012) agrees, where findings showed that people with dementia who received PAC had statistically significant higher mental well-being scores as compared with those who did not, suggesting a less problematic psychological adjustment to receiving a diagnosis of dementia. Lecouturier et al. (2008) argue that as PAC appears to help prepare people with dementia and their families for diagnosis disclosure, it should be conducted at the beginning of an individual's dementia journey. This is owed to PAC establishing patient preferences for disclosing diagnosis, who this is shared with, as well as raising the possibility that just as dementia could be a potential outcome, it may be that no diagnosis can be confirmed. Jha et al. (2012) concur, where the findings of their preliminary study supported the value of integrating PAC to people with mild cognitive impairment as well as early onset dementia. This review identified that when PAC is included in a person’s dementia journey, that person can be assisted in psychologically adjusting to accept and receive a diagnosis of dementia. The literature suggests that well-being is maintained or improved where PAC has been applied.

Pre-Assessment Counselling Delivery Supports Healthcare Professionals with Quality Service Provision

Studies noted that providing PAC to service users enhances service provision quality. The potential influence of PAC on the quality of diagnostic delivery raises important questions about whether its structured approach might address known gaps in clinician confidence and communication skill during disclosure. According to Lecouturier et al. (2008), there is limited evidence on how best to disclose a diagnosis of dementia to people with dementia and their families. They suggest that if healthcare professionals are not confident in using terminology and their approach to diagnosis delivery, then the quality of the diagnosis process is diminished. Lecouturier et al. (2008) also note that very little time is spent elaborating or explaining the diagnosis, which O’Malley et al. (2020) echoes. They argue that PAC is essential in supporting this as it can be comprehensive enough to incorporate potential diagnosis outcomes, reduce confusion and misconception, and enable understanding. Indeed, 100% of O'Malley et al.’s participants, all of whom were healthcare professionals, concurred that PAC was essential to include and thus improved the quality of the dementia diagnosis journey of any individual.

Typically, people with dementia are referred to memory assessment services and community mental health teams (CMHT) for dementia assessments. Rubinsztein et al. (2015) argued that the memory assessment services were able to offer more systematic and comprehensive care because they included services such as PAC. Data in both groups were similar, and a data extraction sheet to assess the quality of each service was developed for the study by using case-note analysis, capturing routinely collected information during assessments by clinicians such as the presence of carer, relative or friend, background characteristics and whether PAC was delivered. These criteria were chosen based on literature evidence, the National Institute for Health and Care Excellence (NICE) guidance for dementia services and the Memory Services National Accreditation Programme (MSNAP) criteria where they could be applied to both services. Though not statistically significant, findings by Rubinsztein et al. (2015) suggest that not only were services in memory assessment services more comprehensive than those found in CMHT services, but that people with dementia also benefit more from the services offered within the former.

Rubinsztein et al. (2015) observed that memory clinic models incorporating PAC appeared to offer more comprehensive and multidisciplinary care. However, the absence of statistically significant differences in outcomes between intervention and control groups raises important questions. Rather than concluding that PAC has no effect, this may reflect methodological limitations such as small sample sizes, outcome measures that were not sensitive to the psychosocial aims of PAC, or variability in how the intervention was delivered. It also highlights a broader issue in the field which is that there is a need for more robust and targeted evaluation methods that align with the intended mechanisms of PAC. The literature review suggests that the quality-of-service provision could be measured, as well as how this impacts the experience of people with dementia and their families receiving a diagnosis through the implementation of PAC.

Pre-Assessment Counselling Brings Family Members into Discussions to Assist them in Supporting their Loved One

This review suggests that PAC may play a vital role in equipping future carers with the knowledge and emotional readiness required to support a person with dementia, though further evidence is needed to substantiate this claim across diverse carer populations. The literature suggested that involving family members in PAC is particularly important. This is because it not only equips them with skills and knowledge to support a person with dementia but also because they are then provided with opportunities to learn and discuss critical issues or concerns.

According to Lecouturier et al. (2008), uncertainty makes it difficult for people with dementia and those who care for them to discuss and plan for the future, and integrating family members into the dementia diagnosis process provides an opportunity for people with dementia and carers to learn and talk together about a potential diagnosis of dementia, and what this means to them. Jha et al. (2012) provided monthly hour-long appointments for people with dementia and their families for up to 6 months with healthcare professionals, which consisted of general conversations around neutral topics or issues and concerns the individual and their families raised. They found that future planning, including legal preparation such as lasting power of attorney, is discussed during PAC suggests its potential as a tool not just for psychological readiness but for promoting practical autonomy and safeguarding long-term decision-making. This could then help provide the person with dementia with the opportunity to hand over control regarding their legal and financial affairs should they lose the capacity to do so in the future.

Discussion

This systematic literature review aimed to critically appraise the evidence and existing literature regarding PAC for dementia. In particular, it sought to focus on the provision of PAC and its benefits and usefulness for people with dementia, family members and healthcare professionals. Overall, although limited in the amount of literature available, there appears to be a consensus that PAC is an essential component of the diagnostic process for dementia and has implications for all parties within the triadic relationship of people with dementia, carers and healthcare professionals. Findings from this systematic review were conceptualised into three themes, namely: (1) pre-assessment counselling enables psychological adjustment of a person with dementia to a potential diagnosis; (2) pre-assessment counselling delivery supports healthcare professionals with quality service provision; and (3) pre-assessment counselling brings family members into discussions to assist them in supporting their loved one.

The results identified that PAC assists people with dementia in adjusting psychologically to a confirmed diagnosis (Jha et al., 2012; Lecouturier et al., 2008). The results of this review align with prior findings that highlight the importance of anticipatory counselling and emotional preparation in other healthcare contexts, such as those discussed in Chapter 1. However, PAC in dementia care pathways may need sustained engagement more than in other health conditions as it emphasises long-term psychological adjustment. The results of this systematic review corroborate with Communication Accommodation Theory (CAT; Giles & Ogay, 2007). CAT highlights the importance of ensuring that all people within the triadic relationship reach the same understanding by adapting communication styles to meet the cognitive and emotional requirements of people with dementia and enhance their engagement and comfort within the sensitive context of PAC. In doing so, healthcare professionals can enable people with dementia to understand more about their condition, enhance feelings of readiness, and mitigate against some of the negative psychological components that can accompany dementia, such as fear, anxiety and feelings of isolation (Giles & Ogay, 2007). Including the principles of CAT within PAC can help develop an inclusive environment that improves and supports people with dementia and increases the confidence of those who will be caring for them, enabling communication to be more cohesive and person-centred. This will contribute to a feeling of preparedness is essential for the diagnosis process (Mastwyk et al., 2014), as literature reports that people with dementia and their families often feel unprepared to receive a diagnosis of dementia (Ducharme et al., 2011; La Fontaine et al., 2014; Mastwyk et al., 2014). The impact of the shock of receiving a diagnosis of dementia can have further consequences, such as people with dementia not accepting their diagnosis (Lai et al., 2023) and mental health implications (Derksen et al., 2006). This is a crucial consideration owing to the high comorbidity of dementia and anxiety and depression in this population (Lueng et al., 2021; Regan & Varanelli, 2013). It is estimated that 38.67% of people who live with dementia also live with depression and anxiety (Lueng et al., 2021), so interventions that improve mental health in this population are essential.

Dementia is frequently diagnosed following a crisis such as hospitalisation or major functional decline (Bunn et al., 2012; Koch & Iliffe, 2010), as some individuals or families initiate assessment following emerging memory concerns. The predominance of crisis-driven diagnoses raises important challenges for PAC implementation, suggesting that early engagement strategies are critical if PAC is to be meaningfully integrated before cognitive decline impairs participation. These help-seeking cases, while less common, tend to involve individuals with greater insight and earlier-stage symptoms and may be more amenable to structured, emotionally attuned interventions such as PAC. In contrast, crisis-driven referrals are often characterised by more advanced cognitive impairment, reduced decision-making capacity, and higher levels of distress, which may limit the immediate benefit of PAC and necessitate a different approach. The distinction between proactive and reactive engagement with services has practical implications for the timing, tailoring and scope of PAC. It demonstrates that there is a need for early identification and careful diagnostic processes that include screening for potentially reversible causes of cognitive change, such as depression, medication side effects, or delirium, before dementia is confirmed (NICE, 2018).

Individuals who present themselves to general practitioners and memory services at the early stages of their cognitive difficulties are likely to have good capacity (Hegde & Ellajosyula, 2016) and, therefore, are potentially able to work collaboratively with healthcare professionals and family members to understand how their comprehension of dementia has been formed. While early-stage capacity theoretically offers an opportunity to address stigma, there is limited empirical evidence confirming that PAC interventions achieve this outcome, underscoring the need for targeted evaluation. As they psychologically adjust to a potential or confirmed diagnosis, they may be able to learn to live well with dementia, something which PAC could help to facilitate. This, in turn, helps reduce anxieties about receiving a diagnosis (La Fontaine et al., 2014). Further, it is common for people with dementia to have reduced self-esteem following diagnosis (Scott, 2022), as previous studies frequently report that they perceive a loss of identity and sense of self (Jetten et al., 2010; Steeman et al., 2013). PAC includes determining a person's current abilities and how activities deemed integral to an individual's identity and enjoyment can be supported following a diagnosis, which supports their mental well-being as they adjust to their condition.

Additionally, a common theme noted in previous studies is that people who are diagnosed with dementia do not wish for other people to know about their diagnosis, primarily due to feelings of shame (Aldridge et al., 2019; Langdon et al., 2007; Riley et al., 2014). PAC can be used to enable conversations to reassure the person with dementia that they have the choice about who they tell. Importantly, not only can these conversations assist in preparedness for a possible diagnosis of dementia but also enable understanding that a confirmed diagnosis may not be given should assessments prove inconclusive. Because many people with dementia wish to know their diagnosis (Elson, 2006; Preston et al., 2007), it can be difficult not to receive a definitive answer to issues experienced. However, a person with dementia and their family must understand that this may be a possible outcome of an assessment and be prepared for this as much as having dementia confirmed. Where time is given to include a PAC appointment as part of routine dementia care in the preliminary stages for a patient, a healthcare professional can ensure that these conversation topics are communicated and comprehended.

The results from this systematic review also show that PAC can positively impact service provision. Findings suggest that by including PAC, healthcare professionals may deliver dementia diagnoses with increased confidence. Evidence exists to suggest that clinicians struggle to determine how people want to have their diagnosis disclosed to them

(Bailey et al., 2019), and healthcare professionals have cited discomfort in disclosing diagnoses and a lack of confidence in the appropriate terminology to use to discuss such a sensitive topic (Giezendanner et al., 2018). By explaining what dementia is and is not in the PAC appointment, people with dementia and their carers can be supplied with the information needed to determine if receiving a diagnosis would benefit them. This in turn, ensures quality, patient-centred care. By being aware of potential outcomes and using the word 'dementia' during initial conversations, healthcare professionals will not need to use euphemisms in diagnosis delivery which can be confusing to an individual who may already have problems with interpreting insinuations (La Fontaine et al., 2014).

Individuals who present themselves to healthcare professionals in the early stages of cognitive decline are likely to still have good decision-making capacity (Hegde & Ellajosyula, 2016) and may be better positioned to work collaboratively with clinicians and family members. This enables early conversations about how they understand dementia and what support they might value. As Chapter 5 later shows, variability in psychological responses even at early stages challenges the assumption that all individuals will equally benefit from PAC, underscoring the need for nuanced engagement strategies. While some individuals express fear or anxiety, others appear unconcerned or disengaged. In some cases, this may reflect emotional resilience or adaptive coping. However, it may also indicate reduced insight or impaired judgement, known features that are associated with certain dementia subtypes and increasingly recognised as part of the disease process itself (Orfei et al., 2010; Vogel et al., 2005). This complexity highlights the importance of tailoring PAC not only to those who are visibly distressed, but also to those who may not fully acknowledge their symptoms. Furthermore, it is important to note that increased confidence following assessment may arise not only from the support provided during PAC, but also from receiving a clear and well-communicated diagnosis, which can provide a framework for understanding symptoms and planning next steps (Carpenter et al., 2008).

Results further disclose that by implementing PAC into dementia care, family members who are likely to care for a person following a confirmed diagnosis of dementia can also benefit. Family members are often as anxious as people with dementia about the diagnosis process, especially so when they have no experience or knowledge of what to expect (Qazi et al., 2010). By including PAC into the dementia care pathway, healthcare professionals can discuss some of the possible outcomes that may arise from a diagnosis with the person experiencing cognitive decline and their family members which will help to converge ways of thinking and understanding within their relationship. People with dementia often deny they have any cognitive issues (Lai et al., 2023) and it is believed that this often stems from fear of the unknown (Parker et al., 2020).

Although people with dementia need to understand the reasons why their family believe that they are experiencing cognitive decline, it is just as important that their family members understand the thoughts and worries of those they care for and how these concerns have been formed, which are then mediated and explored through the PAC appointment. A theoretical model that helps describe the importance of including family members within PAC is the Family Systems Illness Model (FSIM; Rolland, 1994). It notes how families respond and adapt to diagnoses that impact not just the person receiving the diagnosis but that they can change the dynamics and interdependency of familial relationships, and this is something that occurs when a person is diagnosed with dementia. When family members are included within PAC discussions, healthcare professionals can then enable mutual understanding between them and the person they care for, offer supportive coping strategies and work through any questions, worries and concerns that they might have. It is important to hold joint discussions with both the person with dementia and those who care for them as the journey of diagnosis and beyond is often shared, meaning that this model demonstrates the provision of better cohesiveness and resilience within the family unit (Rolland, 1994). Using the FSIM as a guiding framework, PAC can, therefore, facilitate a supportive network that enhances both patient and family well-being throughout the dementia journey.

Whilst joint and separate discussions each have their own merits, it could be argued that unless conversations are held jointly, it will not be possible to ensure dyadic harmony between people with dementia and their carers (Brodaty & Donkin, 2009). Gaugler and Kane (2015) suggest that conversations are more transparent as miscommunication is reduced when they are held between both the person with dementia and their carer and information is exchanged simultaneously. Additionally, any conflicting perspectives can be supported and resolved by the healthcare professional through the PAC appointment should they occur, meaning that they can make decisions together. Conversely, although separate conversations with each party have their uses when seeking to sensitively manage individual concerns, they can also inadvertently result in contrasting expectations or misunderstanding which can prevent an aligned and cohesive approach to dementia care (Ortega et al., 2014). Rather, when joint discussions occur, the relationship between the person with dementia and their carer is reinforced, meaning that a shared view as to how to approach the challenges related to dementia is enabled. Such harmony allows both parties to mutually acknowledge the impact of cognitive decline on the person's quality of life, facilitating agreement on whether it is the right time to explore the underlying cause of these issues. Furthermore, PAC offers carers the opportunity to discuss concerns, and it also helps healthcare professionals build confidence in their ability to deliver sensitive and potentially distressing diagnoses. This alignment not only makes the diagnostic journey smoother for all involved (Ashbourne et al., 2021) but also increases the likelihood that the person with dementia will engage in pre-diagnostic conversations and post-diagnosis interventions (Geshell et al., 2019; Kwak & Radhakrishnan, 2019), which benefits both them and their primary carers.

Limitations and Suggestions for Future Research

Though the findings from this review suggest PAC has some benefits to offer, several limitations must be considered. Firstly, there may be reporting and selection biases in the studies included in this systematic review, possibly reducing its reliability (Tripepi et al., 2010). This is further compounded by the small number of empirical studies that met the inclusion criteria as it limits the generalisability of the findings, which must therefore be viewed with some caution. The few studies included in this review were published only in English owing to the potential for misinterpretation as well as resource constraints for translation. Grey literature was also excluded to enable methodological rigour; however, whilst such exclusions could possibly be viewed as limiting the scope of evidence, they guarantee the accuracy and the robustness of the conclusions drawn (Hartling et al., 2017). Furthermore, this systematic review was limited by the need for more research on PAC. The mixed-methods nature of the included research compounds this limitation, preventing a comprehensive understanding of PAC. In practice, PAC aims to be person-centred, favouring timely diagnoses over quick diagnoses (La Fontaine et al., 2014); however, this was not reflected in the available literature. These limitations demonstrate the requirement for more research to be undertaken in PAC within the dementia care pathway, highlighting people with dementia and their carers profit from the service, particularly exploring if PAC impacts upon the willingness of people with dementia to engage with dementia services at an early stage, possibly addressing barriers that contribute to delayed dementia diagnoses. Another limitation is that all papers selected for the review were from the UK. Despite dementia being a global issue, counselling is generally more accessible in countries with more abundant resources (Volpe et al., 2020). A significant limitation lies in the need for a universal definition of PAC and its clinical practice. The absence of a universal definition and standardised clinical model for PAC complicates both its evaluation and its potential for systematic integration into dementia care pathways. As mentioned in Chapter 1, every memory assessment service in the UK performs some form of PAC, but the approach needs to be standardised. Counselling could range from a brief 10-minute discussion about the benefits of an early diagnosis to an hour-long session covering specific topics in detail.

Further research is required to explore the optimal time of PAC and determine the frequency of sessions as people with dementia and their carers may benefit from a series of appointments providing continuous support provision to manage the psychological impact that accompanies a diagnosis of dementia. Future research should also examine the elements of PAC that benefit people with dementia and their carers, which could contribute to the development of a standardised approach that ensures optimal support through consistent delivery. Further research is required to explore the long-term effects of PAC on the outcomes of people with dementia and carers to establish if receiving an intervention such as PAC early on in the dementia care pathway has any lasting effects and benefits as the condition progresses. Further research should also seek to understand the views of what PAC should look like from the perspectives of the healthcare professionals who conduct it. It should explore the impact and the value of PAC upon people with dementia and their carers, as well as comparing this with those who have not been in receipt of this service. Dementia is one of the most feared components of ageing (Yun & Maxfield, 2020), and further studies are required to investigate how PAC impacts upon fear of dementia and the well-being of people living with cognitive decline when applied at the earliest stages of the diagnosis journey. Studies should also seek to determine if PAC is effective in reducing stigma and self-marginalisation. The remainder of this thesis seeks to address many of the issues discussed here.

Conclusion

This systematic review has highlighted how PAC, when positioned at the beginning of the diagnosis journey, has the capacity to be a critical component within the dementia care pathway. PAC's potential to strengthen the diagnosis journey by facilitating psychological adjustment, carer preparation, and clinician confidence highlights its promise. However, these benefits require further empirical validation across diverse settings. In spite of these encouraging findings, the review also pointed out several limitations, such as a lack of studies, disparities in methodologies, and a geographic focus on the UK, which restrict the generalisation of the results. The absence of a standardised definition and method for PAC further complicates its implementation and assessment across various settings. In order to address these, further research is required to determine what PAC best practice should look like, investigate the effectiveness PAC has in reducing fear of dementia in people living with the condition, and its impact upon the well-being of carers. In doing so, it may be possible to optimise the role of PAC within the dementia care pathway to make sure that the benefits found within the studies of this review are experienced more widely across diverse populations and healthcare services.

Chapter 3: Assessing the Impact of Pre-Assessment Counselling on Dementia Diagnosis and Patient Outcomes in a Memory Assessment Service: A Service Evaluation

The systematic review presented in Chapter 2 found that PAC can help family members in discussions to help them assist their loved one and, that through its delivery, healthcare professionals are supported to give quality service provision. It also noted and is most pertinent for this chapter, that PAC enabled psychological adjustment of people with dementia to a potential diagnosis. This is because PAC is thought to alleviate fear and stigma held by people with dementia and may improve quality of life where it is implemented. Fear and stigma are not the only reasons why someone might refuse to proceed to an assessment for dementia, however. Reasons for accepting or refusing assessments for dementia and the potential outcomes that follow these are as diverse as individuals themselves.

Chapter 2 synthesised the limited literature on what PAC looks like in dementia care and explained some of the ways in which it is useful. This chapter builds on these insights by exploring what PAC looks like in practice within a specific memory assessment service setting. Using historical data, this chapter aims to construct a clearer picture of how PAC is delivered on the ground, who the service users are based on their demographic characteristics, and who ultimately benefits from the service, including those who may opt not to proceed with an assessment. Whilst it cannot directly address the motivations behind individuals’ decisions to engage or disengage with assessment, identifying demographic patterns among those who decline assessments can offer insights about populations potentially missing out on this service. Understanding such patterns was valuable, as it could reveal whether there are specific groups who may need targeted outreach to ensure equitable access to PAC’s potential benefits.

This chapter presents a retrospective service evaluation based on historical patient data collected from a memory assessment service. The aim of this evaluation is to describe patterns of service use and demographic trends among people who attended PAC appointments, rather than to determine causality or formally assess the effectiveness of PAC. By exploring associations between demographic factors and service outcomes, this chapter seeks to provide insights into how PAC was implemented in practice and to identify potential areas for future service development.

Importance of Understanding the Demographic Influences on Dementia Diagnosis

Much literature has found significant correlations between dementia prevalence, age, gender, ethnicity, and dementia outcomes, which the present study focuses on. For example, the risk of developing dementia increases with age (Campbell et al., 2016; Podcasy & Epperson, 2022; Tang et al., 2017). Similarly, gender is known to interact with age, meaning that the risk patterns over a person's lifespan can be altered. For example, women are more likely to be diagnosed with dementia than men as symptoms are usually noticed earlier in the progression of dementia than they are in men (Podcasy & Epperson, 2022). Furthermore, healthcare behaviours in women tend to be higher in incidence than in men, where women more frequently seek clinical advice regarding health concerns than men do (Thompson et al., 2016). As such, these demographic factors have ramifications on dementia outcomes and determine a need for their appraisal within the context of the delivery of PAC and the uptake of subsequent dementia assessments.

It is widely reported in literature that there is a significant relationship between ageing and an increased likelihood of developing dementia (Campbell et al., 2016; Podcasy & Epperson, 2022; Tang et al., 2017) and whilst identifiable modifying risk factors such as smoking, brain injury, diabetes and obesity have been a primary focus of many investigations, the two strongest predictors of dementia – age and gender – are not amendable. Further, gender interacts with age during development across the lifespan to alter the risk of dementia, promoting risk resilience concerning health outcomes where males are less likely to be diagnosed with dementia, and women are often diagnosed earlier in the course of dementia progression, potentially confounding postdiagnosis longevity (Podcasy & Epperson, 2022). Thompson et al. (2016) observed that women were more likely than men to visit their GP for both mental and physical health concerns. Factors such as age, trust in healthcare practitioners, and chronic conditions were significant predictors of healthcare-seeking behaviour, offering insights for the development of healthcare initiatives. Approximately one in five individuals aged over 80 live with a type of dementia, with Alzheimer's Disease being the most prevalent among both younger and older adults (Campbell et al., 2016) and accounts for 60-80% of all dementia diagnoses with almost a twofold increased risk in women versus men. Vascular dementia accounts for 10-20% of dementia diagnoses, where risk factors are more common in males but have greater severity of impact in females (Podcasy & Epperson, 2022). Mixed dementia is usually a mix of

Alzheimer's Disease and vascular dementia and is more common in males (31%) than females (25%) (Podcasy & Epperson, 2022).

Further gender differences include dementia-related anxiety. Literature suggests that females are more worried than men about developing dementia (Tang et al., 2017; Yun & Maxfield, 2020). In a study by Tang et al. (2017), 62.6% of female participants reported being afraid of getting dementia, and those who were most afraid of getting dementia were significantly more fearful of a diagnosis than of other diseases, such as stroke, cancer, or HIV for example than those who were not afraid of getting any disease. The study noted that gender, age and carer status were significantly associated with the level of worry, where carers for people with dementia were more worried than non-carers about developing dementia and were more worried than those who cared for people with other health conditions.

Almost 47.1% of the participants, irrespective of gender, indicated that they would probably or very likely seek screening or testing for dementia if they were noticing cognitive changes (Tang et al., 2017). There was a noticeable difference in screening willingness between males and females, with females showing a significantly higher likelihood of agreeing to undergo screening. This is a problem because it is widely reported that early diagnosis of dementia results in better quality of life outcomes (Logsdon et al., 2007; Mate et al., 2012; Smith et al., 2005; Weimer & Sager, 2009).

While this service evaluation identified patterns related to gender and age among those accessing PAC, important social determinants such as education and socioeconomic position (SEP) were not consistently captured in the data. This represents a notable limitation, as individuals with higher levels of education and SEP are more likely to recognise symptoms, seek earlier assessment, and navigate referral systems effectively (Cooper et al., 2016; Mukadam et al., 2011). Greater health literacy and familiarity with healthcare structures may also influence how people respond to pre-assessment counselling potentially skewing results in favour of those who are already more advantaged. As such, findings should be interpreted with caution, recognising that the sample may not reflect the full diversity of people affected by dementia or the barriers some groups face in accessing support.

One observed gender pattern was that women were more likely to attend PAC sessions than men. While this finding has been reported elsewhere (Greenwood & Smith, 2016), it may not necessarily indicate a gendered preference for help-seeking or service engagement. An alternative explanation could lie in population-level differences in life expectancy and health outcomes. Men are more likely to die earlier from cardiovascular comorbidities that are also associated with dementia risk, resulting in a greater proportion of women surviving into older age and accessing diagnostic services (Office for National Statistics [ONS], 2023). This possibility highlights the importance of interpreting demographic trends in the context of broader mortality and morbidity patterns.

Another significant factor which impedes upon diagnosis include the issues that ethnic minorities have with dementia and the route to diagnosis. Controversially, in the UK, Tuerk and Sauer (2015) note that African-Caribbean individuals are well-represented in memory assessment services. However, they were diagnosed with dementia roughly 4.5 years earlier than British Caucasians and were more often diagnosed with vascular or mixed dementia rather than Alzheimer’s Disease. Conversely, this study found differently. Despite being well represented, initial cognitive testing produced significantly lower scores for African Caribbeans, which potentially indicates more advanced dementia at the time of presentation. This is an issue because delayed dementia diagnoses lead to missed opportunities for potential treatment and increase patient and carer burden (Bradford et al., 2009). Pham et al. (2018) examined dementia diagnosis trends among UK ethnic groups. Their findings revealed that dementia diagnoses were 18% less common among Asian women and 25% more common among black women when compared to white women. Among men, dementia diagnosis rates were 28% higher in the black ethnic group and 12% lower in the Asian group compared to British Caucasians. Delays in timely diagnoses are common for people from ethnic minorities (Brijnath et al., 2021) and have been attributed to inadequate identification of early symptoms of dementia, misunderstanding the changes as normal ageing for which medical attention is not required. Cultural perceptions of cognitive health can lead to neuropsychiatric symptoms being misinterpreted as signs of insanity or madness, resulting in family members concealing the condition (Brijnath et al., 2021; Tillmann et al., 2019). Family preparedness and acceptance of a dementia diagnosis greatly influence its practical implications (Brossard & Carpentier, 2017).

The characteristics of people accessing memory clinics often differ markedly from those represented in population-based studies of dementia risk (van Harten et al., 2013). Clinic-based samples are shaped by help-seeking behaviour, referral pathways, and local service structures, which are themselves influenced by social, cultural and economic factors

(Bunn et al., 2012; Mukadam et al., 2011). As such, those who enter the service for an assessment for dementia are not necessarily representative of the broader at-risk population and, therefore, findings drawn from these groups must be interpreted within this context.

This service evaluation identified several important demographic and social patterns among PAC recipients including the overrepresentation of White British individuals and the high proportion of patients who attended appointments unaccompanied. These findings raise questions about potential inequalities in access, engagement and culturally appropriate service provision. Existing research has shown that people from ethnic backgrounds often face additional barriers to timely diagnosis, including stigma, mistrust of services, language differences and a lack of culturally adapted information (Kenning et al., 2017; Livingston et al., 2020). Furthermore, cognitive tests used to assess dementia may not be appropriate for all cultural or educational backgrounds, increasing the risk of misdiagnosis or underdiagnosis (Dotchin et al., 2014). These disparities have implications not only for diagnostic accuracy but also for the perceived relevance and acceptability of PAC.

While population-based studies offer insights into the risk factors of dementia at a societal level, the present evaluation is based on a clinic-referred sample and must be interpreted within that methodological context. Individuals who access memory clinics often do so via formal healthcare referrals, following observable functional decline or concern from others. As such, this group is not representative of the general population as they are typically older, more symptomatic and more likely to be health-seeking or supported by proactive carers (Bunn et al., 2012; Mukadam et al., 2011). This distinction is important when interpreting demographic patterns and service engagement. The earlier discussion of help-seeking behaviour must therefore be understood not as a generalised reflection of dementia pathways.

Many individuals who experience cognitive decline do not recognise their symptoms or delay seeking help due to impaired insight or psychological denial. Orfei et al. (2010) estimate that up to 60 percent of people with early onset Alzheimer’s Disease exhibit anosognosia, a clinical unawareness of their deficits. This has direct implications for who engages with services like PAC, as those with reduced insight may be less likely to self-refer, attend appointments, or accept support. This may partly explain demographic trends observed in the data, such as higher rates of female attendance, since women are generally more likely to seek healthcare and live longer, thus increasing their visibility in clinic-based samples

(ONS, 2023). These patterns highlight how clinical populations reflect a combination of cognitive, social, and structural factors, and why interpretation of service evaluations must attend carefully to both who is represented and who may be missing.

The person who cares for an individual who is exhibiting cognitive decline can impact the process to diagnosis. Large numbers of individuals who experience cognitive decline are in denial that something could be wrong (Parker et al., 2020). For those who care for people living with suspected dementia, the desire to know that something is wrong to diminish uncertainty and enable forward planning is often a driving source in healthcare-seeking (Bradford et al., 2009). Carers may reframe events to persuade those they care for to seek a medical consultation. Campbell et al. (2016) provide an example, such as a carer comparing a cognitive health check with the GP to a car's annual MOT, emphasising the importance of regular assessments. However, longstanding personal relationships often bring about persistent pressure to seek medical advice, which can lead to relational conflict. Facilitating smoother transitions from personal recognition of illness to professional evaluation is crucial for improving service awareness, access to support, and opportunities for individuals to manage dementia effectively (Bradford et al., 2009). PAC can help support this by enabling a conversation between the healthcare professional, the person with dementia, and their carer, allowing them to discuss any concerns they have noticed or experienced and to determine the support needed moving forward (La Fontaine et al., 2007). Brossard and Carpentier (2017) note that dementia symptoms gradually increase in noticeability as memory lapses, disorientation and uncommon behaviours. Justifications such as grief, retirement or normal ageing lose their plausibility and professional explanations are sought. Implications of this link back to the benefits of early diagnosis of dementia, not just for the person with dementia but also for carers in terms of enabling appropriate support to help them to feel comfortable and confident in their caring role. Anxiety, depression and burnout are common for those who care for people with dementia and with timely diagnoses, earlier interventions can be implemented for carers (Alves et al., 2019; Piersol et al., 2017).

Method

Study Context

Although it is standard practice for GPs to refer individuals with suspected cognitive decline to memory clinics (NICE, 2018), in reality, underdiagnosis remains a significant issue. Research has shown that dementia is often unrecognised or misattributed in primary care with contributing factors including time constraints, diagnostic uncertainty and insufficient training (Dhedhi et al., 2014; Ford et al., 2019). Therefore, the referral pathway may be inconsistently applied. In England, 71% of MAS are accredited by the Memory Services National Accreditation Programme (MSNAP), a quality improvement initiative led by the Royal College of Psychiatrists (RCPsych, 2010). Accreditation is awarded to services that meet criteria across domains such as accessibility, person-centred care, multidisciplinary working, carer involvement, and cultural competence. These standards are evaluated through structured self-assessment, submission of evidence, and site visits by a peer review team, ensuring that participating services align with nationally agreed benchmarks for high-quality dementia care. The Early Intervention Service (EIDS) team is a memory assessment service in Worcestershire and has been providing PAC to people with dementia and their carers since 2010. It is an MSNAP-accredited service. EIDS' primary goals align with MSNAP's values: to facilitate early diagnosis, to support individuals and families through the diagnostic process, and to offer needs-led, person-centred support for people with dementia. To deliver on these goals, EIDS utilises a multi-disciplinary team approach, comprising Band 6 nurses, occupational therapists, support workers, consultant psychiatrists, and clinical psychologists. Together, they deliver high-quality PAC sessions and post-diagnostic interventions to help individuals understand and adjust to their diagnosis and establish plans for future care and support.

On average, EIDS processes 19 referrals per week and offers approximately 24 PAC appointments. This increased capacity reflects adjustments made post-COVID-19 to address waitlists and underscores EIDS's commitment to meeting community needs. PAC sessions are conducted by trained Band 6 nurses and occupational therapists (OTs) who guide people with dementia through the expectations, potential outcomes, and emotional aspects of dementia diagnosis. PAC serves as a preparatory step, encouraging people with dementia to take ownership of their healthcare decisions, including the choice of whether to proceed with an assessment for dementia. It further supports carers, helping them engage with the diagnostic process and enabling a smoother transition to caring responsibilities, should the diagnosis confirm dementia.

By investigating historical data from EIDS, this study aims to gain a deeper understanding of PAC's demographic reach within Worcestershire. Examining patterns in service use, engagement, and outcomes across different demographic groups allows us to identify populations who may be underserved or less likely to engage with PAC. Understanding the disparities in PAC uptake was considered necessary as this could lead to targeted efforts to promote access to the intervention. Therefore, this Chapter seeks to determine if uptake is influenced by specific characteristics and, if so, how these might inform and shape the approach of PAC and its delivery.

This study evaluated demographic trends among individuals referred for dementia assessment, with a particular focus on who consented to proceed following PAC. Rather than assessing the clinical efficacy or psychological benefit of PAC itself, this service evaluation used historical patient data to understand which groups are more or less likely to engage with diagnostic assessment. As such, it is not a risk factor analysis but rather an exploration of help-seeking and consent behaviours within a real-world service context. Identifying differences in consent rates by demographic characteristics such as gender, age, ethnicity, and marital status, provides insight into how equitable access to PAC and diagnostic services is at present and where outreach or adaptation might be necessary.

Study Design and Sample

The EIDS team provided 11,361 anonymised electronic patient records for analysis. Records were eligible for inclusion if they contained complete information on key demographic variables (age at referral, gender, ethnicity, marital status, and main supporter) and patient outcome data. Records were excluded if these fields were missing or incomplete. Data for this evaluation were reviewed between March 2022 and June 2022. No clinicians were involved in the review process; the evaluation was based solely on anonymised historical patient records provided by the EIDS team. A large number of patient data fields were not fully populated, severely limiting the number of records that could be used for analysis. This, coupled with further data cleansing, resulted in 3044 records being eligible for consideration. The dataset underwent several stages of review and cleaning prior to analysis. First, a manual inspection of the anonymised records was conducted to identify and remove duplicate entries and to check for inconsistencies in data formatting across key variables. Frequencies were generated for all variables to assess the extent of missing values, and only records with complete data on key demographic and outcome fields were retained. Ethnicity was recoded into two categories (White British vs non-White British) due to low numbers in several ethnic subcategories, and diagnostic data were also grouped to distinguish between Alzheimer's Disease and other diagnoses for analysis. Of this number, 1291 (42.21%) were male and 1753 (57.59%) were female. Ages ranged from 28 to 114 years (mean = 78 years, standard deviation = 9 years). Table 3 shows the total number of participants within their demographic categories and how these are split between those who consented to an assessment that led to a dementia diagnosis and subsequently were referred back to the GP for their post-diagnostic care and those who did not consent to undergo an assessment.

Table 3

Participant split between variable groups according to demographic categories

Predictor variables	*N*	% *N*	Referred to GP	% Referred to GP	Declined Assessment	% Declined Assessment
Gender						
Male	1291	42.41%	732	24.05%	263	8.64%
Female	1753	57.59%	911	29.93%	390	12.81%
Ethnicity						
White British	2986	98.09%	1634	53.68%	636	20.89%
Non-White British	58	1.91%	9	0.30%	17	0.56%
Marital Status						
Married/civil partnership	1828	60.05%	1009	33.15%	391	12.84%
Cohabiting	44	1.45%	30	0.99%	9	0.30%
Divorced/separated	138	4.53%	65	2.14%	21	0.69%
Single	60	1.97%	22	0.72%	13	0.43%
Widowed	974	32.00%	517	16.98%	219	7.19%
Main Supporter						

Spouse/partner	1834	60.25%	1030	33.84%	397	13.04%
Child/other family member	1073	35.25%	545	17.90%	220	7.23%
Friend/neighbour	102	3.35%	56	1.84%	35	1.15%
Professional support	26	0.85%	12	0.39%	9	0.30%
Other/unspecified	9	0.30%	1	0.03%	2	0.07%

The catchment area for EIDS is Worcestershire, a county in the West Midlands of the UK. The population of Worcestershire is 604,947, according to mid-2022 population figures published by the Office for National Statistics (ONS, 2022). Population by race from the 2021 census shows that 93.8% of people are White, 3.1% are Asian, 1.9% are Mixed, 0.7% are Black, and 0.6% are Other. English is spoken as the main language by 95.6% of the people in Worcestershire and is spoken either ‘well’ or ‘very well’ by 4% of the population. 0.7% reported poor English skills, and the remaining 0.1% spoke no English. Worcestershire comprises eleven built-up area subdivisions with 5,000 or more inhabitants including Worcester (103,617), Redditch (86,996), Kidderminster (57,400), Malvern (79,973), Bromsgrove (99,475), Evesham (27,684), Droitwich (25,027), Stourport-on-Severn (20,653), Catshill (10,169), Bewdley (9,267), and Pershore (8,406).

This study was conducted as a service evaluation and did not require NHS Research Ethics Committee approval in accordance with UK Health Research Authority (HRA) guidance. Prior to data access, the research team contacted the NHS Trust responsible for the dataset to clarify access requirements. The Trust’s Research and Development (R&D) department reviewed the researcher’s credentials and confirmed that the evaluation fell within service evaluation governance frameworks. The researcher held a valid research passport and was subsequently issued an honorary NHS contract. Secure remote access to the anonymised dataset was provided through the Trust’s internal systems, in accordance with NHS information governance protocols.

This service evaluation was approved by Herefordshire and Worcestershire NHS Health and Care Trust (ref: JB/ajo/par), and by Nottingham Trent University ethics committee (ref: 1537495). The analysis used anonymised historical data provided by the EIDS team in the form of electronic medical records of people suspected of having dementia who had been referred to the EIDS team by their GP and had undergone PAC. Variables from the service records included age, gender, consent for assessment, and refusal to proceed to assessment following a PAC appointment.

The predictor variables used in this study included the age of the patient when they were referred by their GP, gender and ethnicity, and the outcome variables were patient outcome and the diagnosis given. These were chosen based upon how particular demographic factors can impact upon healthcare-seeking behaviours within dementia care pathways. Age at referral is frequently associated with varying responses to cognitive decline and the likelihood of seeking assessment, with older individuals potentially more inclined to engage with healthcare services as cognitive symptoms progress (Campbell et al., 2016; Podcasy & Epperson, 2022; Tang et al., 2017). As formerly noted, gender is a significant demographic factor in health-seeking behaviour as studies have noted the correlation between gender and attitudes towards assessment where women tend to be proactive in maintaining general health and engage more with the clinicians who provide it, possibly influencing their decisions to proceed to assessment (Thompson et al., 2016). The inclusion of ethnicity was owed to evidence that suggests that systemic and cultural factors can impact upon health-seeking behaviours, including those to dementia care services, with particular ethnic groups experiencing delays in getting diagnosed (Pham et al., 2018). The selection of patient outcome and diagnosis as outcome variables aligns with the study's objective to assess how demographic predictors influence both diagnostic decisions and post-diagnostic pathways. As the study seeks to inform improvements in dementia care delivery, particularly through targeted pre-assessment counselling interventions, understanding these relationships is critical.

The variables selected for further examination included age at referral, gender, ethnicity, marital status, main supporter, patient outcome, and diagnosis. The predictor and outcome variables included within this study are congruent with previous research, providing justification for their use in measuring how this may impact outcomes. It is widely accepted that age advancement correlates with risk of developing dementia, as well as between stage of dementia and engagement with healthcare professionals (Campbell et al., 2016; Podcasy & Epperson, 2022; Tang et al., 2017). Gender was included as it has been shown to affect health-seeking behaviours where women engage more than men with healthcare services, meaning that this could have consequences on the number of dementia diagnoses (Thompson et al., 2016). The inclusion of ethnicity was owed to findings determining that systemic and cultural factors exist that impact upon access to dementia care services with particular ethnic groups experiencing delayed diagnoses (Pham et al., 2018). Lastly, the marital status and the main supporter of the person with dementia were included as these are recognised factors that impact upon diagnosis outcomes and capture the relational dynamics and social support of someone with dementia (Lai et al., 2022; Sommerlad et al., 2018).

This study splits ethnicity into two levels: white British and non-White British. This is because the vast majority of patients were white British, making it difficult to gain meaningful insights from individual ethnic subcategories with smaller numbers. Marital status was split into five levels: married/civil partnership, cohabiting, divorced/separated, single, and widowed. The main supporter variable was also split into five levels: spouse/partner, child/other family member, friend/neighbour, professional support, and other/unspecified. Patient outcomes included in this study were referral back to GP (indicating that an assessment and diagnosis had taken place), declined assessment (indicating that the patient decided not to proceed further on their diagnosis journey following PAC), and other outcomes such as referral to community mental health teams (CMHT). Community Mental Health Teams (CMHTs) are multidisciplinary teams that provide assessment, treatment, and support to people with complex mental health needs, including older adults with suspected dementia. They often play a key role in referral, diagnosis, and post-diagnostic care in the community (NHS England, 2019). Diagnosis was split into two levels: Alzheimer’s Disease and Other diagnoses. This was because Alzheimer’s Disease is the most frequent type of dementia to be diagnosed (Li et al., 2017). However, other diagnoses include vascular dementia, mixed dementia, and mild cognitive impairment (MCI).

Statistical Analysis

All of the analyses were conducted using SPSS Windows 28. Chi-square tests were used to analyse relationships between the categorical variables including gender, ethnicity, marital status, and the main supporter, to determine if there were significant relationships with patient outcomes and their diagnoses. Chi-square analysis was used to analyse the categorical variables because it identifies relationships without assuming any data distribution, making it appropriate for variables with multiple discrete categories (Kishore & Jaswal, 2023). Marital status and main supporter categories were split into five levels each to explore their influence in detail. These groupings are indicated in Table 4.

Table 4

Groups of variables used for Pearson Chi-square analyses.

Predictor variables	*N*	Percentage
Age at referral	3044	
Gender		
Male	1291	42.41%
Female	1753	57.59%
Ethnicity		
White British	2986	98.09%
Non-White British	58	1.91%
Marital Status		
Married/civil partnership	1828	60.05%
Cohabiting	44	1.45%
Divorced/separated	138	4.53%
Single	60	1.97%
Widowed	974	32.00%
Main Supporter		
Spouse/partner	1834	60.25%
Child/other family member	1073	35.25%
Friend/neighbour	102	3.35%
Professional support	26	0.85%
Other/unspecified	9	0.30%

Outcome variables	*N*	Percentage

Patient Outcome		
Deceased	39	1.28%
Declined Assessment	653	21.45%
Declined feedback after assessment	22	0.72%
DNA	5	0.16%
Hospitalised	15	0.49%
No evidence of dementia detected	192	6.31%
Other	49	1.61%
Referred back to GP	1643	53.98%
Referred to CMHT	419	13.76%
Referred to another team	7	0.23%
Diagnosis		
Alzheimer’s Disease	662	21.75%
Dementia unspecified	161	5.29%
Depression	30	0.99%
Frontotemporal dementia	24	0.79%
Lewy Body dementia	65	2.14%
Logopenic dementia	2	0.07%
MCI	176	5.78%
Mixed dementia	272	8.94%
Other	59	1.94%
Posterior Cortical Atrophy	9	0.30%
Progressive non-fluent aphasia	14	0.46%
Semantic dementia	9	0.30%
Vascular dementia	265	8.71%
(Blanks)	1296	42.58%

Independent samples *t*-tests were used to assess differences in continuous data (e.g., age) between two groups, such as diagnosis categories. *T*-tests are ideal for examining the mean differences among categorical groups, offering insights into how age influences diagnoses. This method was suitable for evaluating whether variables such as marital status and main supporter affected age-related differences in diagnosis and patient outcome categories.

Logistic regression was employed to estimate the likelihood of particular outcomes, such as receiving a diagnosis of Alzheimer’s Disease, influenced by several predictors, including age, gender, and ethnicity. This technique considers the combined effect of various predictor variables, highlighting how demographic factors like age, gender, and ethnicity independently affect diagnostic results. In this model, gender was coded as 1 = male and 2 = female.

Results

Diagnostic Analyses

A logistic regression was performed to ascertain the effects of gender (male and female), age at referral and ethnicity (White British and non-White British) upon the likelihood of patients being diagnosed with Alzheimer’s Disease (Table 5). The logistic regression model was statistically significant, $\chi 2(1, N=662) = 18.01$, $p < 0.001$. The model explained 0.2% (Nagelkerke R2) of the variance in dementia diagnoses and correctly classified 62.1% of cases. Females were 1.5 times more likely to be diagnosed with Alzheimer’s Disease than males (OR=.66, 95% CI [.54, .81]). Ethnicity was not associated with dementia diagnoses, but increasing age was associated with an increase in the likelihood of being diagnosed with Alzheimer’s Disease (OR=.98, 95% CI [.97, .99]).

Given its appropriateness for binary outcomes and its capacity to assess the effect of individual predictor variables on the probability of an Alzheimer’s Disease diagnosis, logistic regression was chosen.

Table 5

Regressions of associations between diagnosis of Alzheimer's Disease and patient demographics

Variable	*B*	*SE*	*p*	Exp(B)	95% CI
Gender	-0.42	0.10	<.001	0.66	[.54, .81]
Age at referral	-0.02	0.01	0.002	0.98	[.97, .99]
Ethnicity	-0.19	0.54	0.72	0.83	[.29, 2.37]

Independent samples *t*-tests assessed differences between age and diagnoses given. The 662 patients who were diagnosed with Alzheimer's Disease (M_{age} = 79.29, *SD* = 7.24) compared to the 2382 patients who received an alternative diagnosis to Alzheimer's Disease (M_{age} = 77.68, *SD* = 9.58) was statistically significant where *t*(3042) = 4.01, *p* = .001. The 265 patients who were diagnosed with Vascular dementia (M_{age} = 80.11, *SD* = 7.01) compared to the 2779 patients who received an alternative diagnosis to Vascular dementia (M_{age} = 77.84, *SD* = 9.30) was statistically significant where *t*(3042) = 3.88, *p* = .001. The 272 patients who were diagnosed with Mixed dementia (M_{age} = 80.99, *SD* = 6.29) compared to the 2772 patients who received an alternative diagnosis to Mixed dementia (M_{age} = 77.74, *SD* = 9.33) was statistically significant where *t*(3042) = 5.62, *p* = .001.

People diagnosed with Alzheimer's disease were, on average, almost two years older than those diagnosed with other forms of dementia. Regression analysis showed that age was a significant predictor of Alzheimer's diagnosis, whereas ethnicity, categorised as White British vs. non-White British, did not significantly influence the diagnostic outcome. This suggests that, once referred to the service, diagnostic decisions were not associated with ethnicity.

Post-Diagnostic Care Analyses

Table 6 shows the results found as a result of a 2x2 chi-square test of independence being conducted to examine the relation between gender (male/female) and post-diagnosis care (referred back to GP vs any other patient outcome). The relationship between these variables was significant, χ^2 (1, N=1642) = 6.70, p = 0.01. Males are more likely to be referred back to the GP than any other outcome. Further to this, analyses on the relationship between ethnicity and post-diagnosis care noted that the relation between these variables was significant, χ^2 (1, N=1643) = 35.20, p < 0.001. White British patients are more likely to be referred back to the GP than any other outcome.

A 5x2 chi-square test of independence was performed to examine the relation between main supporter (spouse/partner, child/other family member, friend/neighbour, professional support, other) and post-diagnosis care (referred back to GP vs any other patient outcome). The relation between these variables was significant, χ^2 (4, N=3044) = 14.85, p = 0.005. Post-hoc testing was conducted using Bonferroni adjusted alpha levels of 0.005, within which the 'spouse/partner' group was significant to the model (p = 0.003), meaning that the category of 'main supporter' showed a significant difference in post-diagnostic care.

A 5x2 chi-square test of independence was performed to examine the relation between marital status (married/civil partnership, cohabiting, divorced/separated, single, widowed) and post-diagnosis care (referred back to GP vs any other patient outcome). The relation between these variables was significant, χ^2 (1, N=3044) = 19.14, p < 0.001. However, when post-hoc adjusted z-score calculations with adjusted Bonferroni correction were conducted to explore the groups that contributed to the difference, non-statistically significant outputs in all comparisons using the adjusted alpha value (0.005) were found.

Table 6

Chi-square analyses between gender x patient outcome, main supporter x patient outcome, and marital status x patient outcome.

Predictor variables	Referred back to GP	Percentage (Referred to GP)	Any other patient outcome	Percentage (Any other patient outcome)
Gender				
Male	732 (696.82) [1.78]	42.73%	559 (594.18) [2.08]	42.04%
Female	911 (946.18) [1.31]	57.27%	842 (806.82) [1.53]	57.96%

Ethnicity				
White British	1634 (1641.92) [0.38]	98.23%	1352 (1344.08) [0.05]	97.93%
Non-White British	9 (1.08) [58.10]	1.77%	49 (56.92) [1.10]	2.07%
Marital Status				
Married/civil partnership	30 (23.75) [1.65]	63.12%	14 (20.25) [1.93]	56.46%
Cohabiting	65 (74.49) [1.21]	1.52%	73 (63.51) [1.42]	1.36%
Divorced/separated	1009 (986.66) [0.51]	4.08%	819 (841.34) [0.59]	5.07%
Single	22 (32.39) [3.33]	2.01%	38 (27.61) [3.91]	1.93%
Widowed	517 (525.72) [0.14]	29.28%	457 (448.28) [0.17]	35.19%
Main Supporter				
Spouse/partner	1030 (990.50) [1.57]	65.19%	804 (843.50) [1.85]	54.46%
Child/other family member	545 (579.50) [2.05]	31.16%	528 (493.50) [2.41]	40.04%
Friend/neighbour	56 (55.09) [0.02]	2.13%	46 (46.91) [0.02]	4.78%
Professional support	12 (14.04) [0.30]	0.97%	14 (11.96) [0.35]	0.71%

Discussion

The statistically significant results from the logistic regression suggest that gender and age at referral are predictors of being diagnosed with Alzheimer's Disease. In particular, females were more likely to receive a diagnosis of Alzheimer's Disease than males, and the likelihood of an Alzheimer's Disease diagnosis increased with older age at referral. These findings align with previous research, where Campbell et al. (2016) noted that females were twice as likely to develop Alzheimer's Disease as males, and this could, in part, be due to females living longer than males (Gregory, 2022). Ethnicity was also included in the analysis, but no significant difference was found between White British and non-White British groups, suggesting that once individuals accessed the service, diagnostic decisions did not vary by ethnicity. This finding contrasts with broader literature that highlights disparities in access to dementia services and culturally influenced understandings of dementia (Sayegh & Knight, 2013). It may be that inequalities exist earlier in the care pathway, but not at the point of diagnosis once assessment is underway.

Analyses of post-diagnostic outcomes showed that males were more likely to consent to assessment and be referred back to GP care compared to females (Campbell et al., 2016; Podcasy & Epperson, 2022). It was also noted that males were more likely to consent to assessment and be referred back to the GP for post-diagnostic care., which contrasted with previous literature. This contrast in findings is especially evident when compared to Tang et al. (2018), who found that females were significantly more willing to be screened for dementia than males.

The differences in findings observed across studies may be partly explained by methodological variations, including whether data were drawn from clinical or population-based samples. Population-based studies typically capture a wider demographic and socioeconomic spectrum (Brayne & Calloway, 1990), while memory clinic-based studies reflect those who actively seek and access formal assessment (Farias et al., 2009). As such, clinic samples may underrepresent individuals from marginalised backgrounds, non-native speakers and those from socioeconomically disadvantaged backgrounds (La Fontaine et al., 2007; Tillmann et al., 2019). Regional differences in service availability, diagnostic criteria and referral practices may also influence patterns of presentation, engagement and diagnosis (Speechly et al., 2008). These methodological factors should be considered when interpreting and comparing results as they have significant implications for equity in dementia diagnosis and access to pre-assessment support such as PAC.

This may indicate that PAC was perceived as useful to males in particular, enabling them with information to assist them in deciding to proceed with an assessment for dementia and then be discharged to their GP, as opposed to any other outcome. Although not statistically significant,females are slightly more likely to decline an assessment for dementia as compared with males, this may be of concern. Primarily because, as previously mentioned, women tend to live longer than men (Gregory, 2022) meaning that women may miss out on interventions that could improve the quality of their lives that proceed a dementia diagnosis (Logsdon et al., 2007).

Although PAC alone may not be sufficient to improve quality of life outcomes, evidence suggests that multicomponent interventions, such as cognitive stimulation therapy, structured psychosocial support, and tailored post-diagnostic programmes like STrAtegies for RelaTives (START), have demonstrated positive impacts on wellbeing and coping among people with dementia and their carers (Livingston et al., 2013; Martyr et al., 2018). Integrating PAC with such interventions may enhance its overall effectiveness by providing continued emotional and practical support beyond the initial assessment phase.

Boustani et al. (2016) suggest that individuals who make mistakes on questions concerning orientation in their cognitive screening test are more likely to proceed to an assessment for dementia, meaning that those who view themselves as being asymptomatic are less likely to agree to undergoing an assessment that could lead to a diagnosis. This is particularly relevant for PAC, which can emphasise the importance of early diagnoses, even if patients believe themselves not to have any symptoms, and prepare them accordingly through discussions aimed at empowering them and overcoming any reluctance to proceed with an assessment. In this way, PAC dispels any myths or misconceptions held towards dementia or the diagnostic journey, which may result in earlier diagnoses and improved outcomes (La Fontaine et al., 2007).

The findings indicated that White British patients were more likely to consent to an assessment for dementia and then be discharged to their GP for their care following diagnosis than non-White British patients, demonstrating an interaction between ethnicity and post-diagnostic outcomes. This aligns with previous literature, where some ethnic groups do not view dementia as a medical condition (Tillman et al., 2019). Although Tuerk and Sauer (2015) note that African-Caribbean populations appear well-represented in memory assessment services, the same cannot be said for other ethnic minorities. This is a problem because the second largest ethnic group in the UK after British Caucasians is Asian (ONS, 2021) and much research is required with these communities to enable an awareness and accurate understanding of dementia (Cheng et al., 2019; Gallagher-Thompson et al., 2003; Sayegh & Knight, 2013).

Additionally, ethnic disparities were evident, with White British participants more likely to be discharged to their GP. This raises important questions about equity in post-diagnostic planning and the cultural accessibility of dementia services. While these findings may reflect wider systemic inequalities, they also underscore the importance of tailoring PAC and follow-up care to better meet the needs of underrepresented and marginalised groups. Where the main supporter of a person with dementia did not come under professional, family, friend or neighbour categories, people with dementia were seldom referred to GPs for their post-diagnostic care. Among those not discharged to GP-led care, the primary reasons were the absence of detected dementia or patients declining assessment. Most people who are diagnosed with dementia are subsequently informally cared for in their own homes by their spouses (Tatangelo et al., 2018), and the individual who would likely care for the person with suspected dementia typically attends the clinical appointments alongside the person with dementia (Morgan et al., 2014). These results, when considered alongside previous research that has noted that individuals who experience cognitive decline often deny that something could be wrong (Parker et al., 2020), suggest that PAC is viewed positively by people with dementia and their families as an assessment for dementia only takes place should the person with suspected dementia consents to do so. As such, PAC may enable acceptance and awareness of dementia by discussing the hope of an opportunity to live well with dementia with support and provision that is less limited should a clinical diagnosis be made.

Communication Accommodation Theory (CAT; Giles & Ogay, 2007) provides a useful theoretical lens for interpreting some of the demographic patterns observed in this service evaluation. CAT suggests that adjusting communication styles to meet the cognitive and emotional needs of individuals improves trust, understanding, and engagement in healthcare interactions. While this study did not directly assess communication practices, the observed outcome differences, such as higher assessment refusal rates among single or unsupported individuals, may reflect unmet communication needs in those without a close relational advocate. In contrast, those with a partner or child as their main supporter were more likely to proceed with diagnostic assessment, which may indicate that the supportive presence of a familiar figure can enhance communication effectiveness and reduce anxiety. Thus, CAT highlights how interpersonal dynamics and tailored communication, as operationalised through PAC, may influence whether people feel safe and supported enough to proceed with diagnosis.

The relationship between marital status and post-diagnostic outcome was also significant, although post-hoc testing determined no single level was the cause. Of the levels, those who were married/civil partnerships, divorced/separated or who were widowed were more likely to be discharged for post-diagnostic care from their GP following consent to dementia assessment and receiving a diagnosis. Single and divorced/separated individuals were more likely to experience alternative post-diagnostic pathways compared to those who were married or in civil partnerships, consistent with previous research.. These findings are somewhat comparable with other studies that have noted relationships between marital status and higher rates of cognitive evaluations and assessments (Fowler et al., 2015; Kotagal et al., 2015). Research by Fowler et al. (2015) explored traits associated with patients who refused diagnostic assessment, noting that living alone was the only demographic factor significantly linked to refusal. Additionally, patients who were not married had higher refusal rates for assessment than those who were married. Further, a study by Kotagal et al. (2015) found that being married was associated with a greater likelihood of undergoing assessment for dementia and suggested that unmarried patients may be more reluctant to divulge cognitive concerns to their GP owing to worries that any ramifications from this disclosure may impact upon their autonomy. Thus, PAC does not appear to change this, as the findings match previous studies.

The significant findings between marital status and diagnostic outcomes raise important implications for PAC as a service. Patients who are married or have a cohabiting partner may experience a more supportive journey through PAC and into post-diagnostic care, as partners provide both companionship and care support. On the other hand, those who are single or living alone may experience heightened uncertainty and reluctance around the diagnostic process. Future research could explore whether adapted PAC sessions that consider relational dynamics and living situations might support greater engagement with assessment.

Strengths and limitations

This study had several limitations that require consideration. Firstly, this study is limited in drawing conclusions when compared to trends reported elsewhere, such as the consistent underrepresentation of ethnic minority groups in memory clinics (Manthorpe et al., 2013; Nielsen & Jørgensen, 2020), and the observation that earlier engagement with assessment services is more likely among people who are White British, female, and of higher socioeconomic status (Brooke et al., 2018). These established trends provide a useful comparative framework but were not fully reflected in the present dataset likely due to regional or service-level differences in PAC implementation.

A key limitation of this study is the substantial reduction in usable patient records, with only 3,044 of the 11,361 anonymised electronic files eligible for analysis. Since the conception of the EIDS team to the present day, there have been two system changes within the NHS which altered the way demographic and outcome data were recorded. As a result, many fields within the dataset were left incomplete or inconsistently populated owing to those fields no longer being available on the new system, restricting the ability to include those cases in statistical analyses. This limitation may have introduced bias by excluding potentially relevant cases and reduced the generalisability of the findings, particularly regarding the representativeness of the full patient population.

Further, the findings of the present study are limited by the research team being unable to ensure representation of the sample. This is something to consider regarding the findings concerning ethnicity and post-diagnostic outcomes. Despite White-British patients being significantly more likely to consent to an assessment for dementia and then be referred to their GP for care following a diagnosis, it is important to consider that of the total participants in this study, non-White British participants account for just 1.91%, and these findings should therefore be viewed with caution. Such results from a small number of non-White British participants in this study cannot be generalised to all non-White British ethnic groups within the UK. Further limitations of this study to consider includes the use of quantitatively analysed historical data. Simonton (2003) suggests that there is a tendency for historical data to be correlational meaning that their internal validity could be considered to be limited. As such, any conclusions surrounding causation must be carefully considered. Conversely, they are considered to have robust external validity.

Future research

Future research suggestions include further exploration into where PAC might be most useful, particularly concerning non-White British populations living within the UK. Though this group makes up a small percentage of the patients seen in a PAC clinic, ethnic minorities are generally under-represented in memory assessment services (Manthorpe et al., 2013). As such, an evaluation of the PAC process, its conversations, and its cultural appropriateness should be conducted to help obtain consent to assessment rates. Further studies should be considered in determining and understanding the reasons made by women who choose not to proceed to assessment. Further, an evaluation of PAC and the dyad of the person with dementia and their main supporter would be valuable. This is not just for groups noted previously where numbers of being discharged to GP care following a dementia diagnosis were lower than alternative patient outcomes, but also for those who are cared for by a child or other family member. As this group is the second largest to those cared for by their spouses or partners, only a little over half of these patients were discharged to their GP for their post-diagnostic care. The usefulness of PAC for people with dementia who are cohabiting and single, as well as patient outcomes, should also be explored, as these individuals may face unique challenges in dementia care. For instance, they may have limited informal support or fewer opportunities for shared decision-making, which could impact their engagement with PAC and subsequent patient outcomes. Examining how PAC can be adapted to meet the specific needs of these groups would be essential for ensuring equitable and effective dementia care. To continue building on the findings of this study, future research should also look into the integration of PAC with digital tools that can enhance access for underrepresented or geographically dispersed communities. PAC could be delivered over the telephone or via video calls and provide timely and remote support, reducing barriers for those in remote locations or with limited transportation. Further, digital PAC solutions might offer additional benefits, such as targeted resources in multiple languages or culturally tailored information, potentially increasing its acceptability among non-White British patients. Such technological enhancements could help bridge gaps in the traditional PAC model, making dementia care services more inclusive and accessible.

One of the most notable findings from this evaluation was that people from non-White backgrounds were just as likely as their White British counterparts to proceed with assessment and receive a diagnosis following the PAC intervention. This suggests that PAC may play an important role in supporting equitable decision-making across ethnic groups regarding whether to pursue a formal dementia assessment. Previous research has documented hesitancy among some minority ethnic groups in accessing dementia services due to stigma, cultural understandings of memory problems, and concerns about the relevance or cultural sensitivity of care (Kenning et al., 2017; Liu et al., 2021). The present findings imply that PAC may help address some of these concerns by providing information and emotional support that enables people with dementia to make more confident and informed choices about assessment.

However, disparities emerged in the post-diagnostic phase. Fewer individuals from minority ethnic backgrounds were discharged to general practitioner-led care, suggesting possible inequities in what happens after diagnosis. It is unclear whether this is due to differences in perceived support networks, communication challenges, or concerns about follow-up care availability in primary care settings. Previous research has indicated that a lack of culturally tailored services and uncertainty about ongoing support may influence discharge decisions (Cooper et al., 2020). Further research is needed to explore the underlying reasons for these patterns and ensure post-diagnostic care pathways are inclusive and responsive to diverse needs.

A similar pattern was observed for those who were single or living alone as they were also less likely to be discharged to GP-led care. Clinicians may have been reluctant to discharge these patients in the absence of a carer who lived with them, which is consistent with concerns about safety, support and social isolation noted in previous literature (Greenwood et al., 2019). While such caution may be well-intentioned, it raises questions about how services can better support people who lack a supportive care network.

These findings highlight the broader potential value of PAC not only in preparing people for assessment, but also in shaping early planning for post-diagnostic care. In particular, they point to a need for future service development to ensure that people from minority ethnic backgrounds and those who are single receive care that is equitable, culturally appropriate, and tailored to their social context (Moriarty et al., 2021).

Conclusion

This study highlights the significant role of PAC in dementia care services. Findings from this evaluation suggest that PAC may support timely diagnosis, which is important for management and planning for people with dementia.. While this evaluation did not directly measure fear or anxiety, PAC may help reduce concerns related to diagnosis by providing information and support. However, comparative data from services that offer PAC is lacking and non-White British populations are underrepresented in this study, proposing that further research should be conducted to ensure the accessibility and the cultural appropriateness of PAC for ethnic groups. Generally, the findings support the integration of PAC into the early stages of the dementia care pathway as findings demonstrate that it improves the experience of diagnosis and the subsequent outcomes for people with dementia.

Chapter 4: Exploring Key Components and Clinical Effectiveness of Pre-Assessment Counselling for Dementia Diagnosis: Perspectives from NHS Healthcare Professionals

Chapter 3 discussed the characteristics of the patients who receive PAC and how those influenced their outcomes. Chapter 4 seeks to expand on this by exploring the views of PAC from the healthcare professionals who deliver it within the memory assessment service. It will investigate the benefits and challenges faced in PAC appointments. By understanding these experiences, this Chapter endeavours to clarify how PAC facilitates early diagnoses and improved outcomes for people who live with dementia.

The Value of Insights from Healthcare Professionals

It is important to explore the perspectives of the healthcare professionals who conduct PAC, given their unique position as those who implement an intervention that remains underutilised and inconsistently embedded within dementia care pathways. Furthermore, they are able to observe the effects of PAC and have experience in adapting how it is delivered depending upon the contextual challenges that they face and the needs of people with dementia and their carers. Understanding these insights provides a nuanced perspective on how PAC aligns with the theoretical benefits discussed in earlier chapters and whether it fully supports people in making informed decisions about proceeding with a dementia assessment. Through analysing healthcare professionals' experiences, this chapter examines whether current PAC practices address common barriers to diagnosis identified in dementia literature, such as social and self-stigma (Nguyen & Li, 2020), limited symptom recognition (Harwood et al., 2000), and GP challenges in diagnosis (Phillips et al., 2012), or if further refinement in PAC delivery is necessary. This chapter aims to explore how the theory and practice of PAC enable more positive outcomes for people with dementia and their carers.

Chapter 3 explored the measurable effects of PAC on outcomes, but how these results are achieved remains unknown and an investigation into the experiential and contextual factors that impact PAC is needed. As such, Chapter 4 explores the reality of PAC in practice, seeking to understand the key components and their effectiveness from the perspectives of the healthcare professionals who deliver these appointments using qualitative research methods. This is to understand not just the strategies the healthcare professionals use and the benefits they offer through PAC, but the interpersonal and systemic challenges that accompany its delivery. By exploring these experiences, this chapter aims to uncover possible deficiencies in the existing PAC framework that could affect the diagnostic journeys of people with dementia, thereby setting the stage for possible improvements in PAC practices.

In this chapter, the term ‘timely diagnosis’ is used in accordance with person-centred care principles. Rather than referring to diagnosis as early as possible in the disease process, ‘timely’ in this context refers to a diagnosis delivered at an appropriate moment for the individual — when they are psychologically ready, when it is clinically appropriate, and when it enables access to relevant support. This understanding reflects the position of the National Institute for Health and Care Excellence (NICE, 2018), which advises that the timing of diagnosis should be tailored to each person’s situation. Similarly, the World Health Organization (WHO, 2012) defines a timely diagnosis as one that occurs at the right moment for the person, not simply at the earliest possible point. This approach is supported in the literature on person-centred dementia care, which recognises that individuals differ in how they experience, understand, and respond to cognitive decline (Iliffe et al., 2009; Bunn et al., 2012). It also reflects arguments that the pursuit of early diagnosis at all costs may undermine autonomy or cause distress, and that timely diagnosis may be more aligned with people’s values and preferences (Dhedhi et al., 2014; Bunn et al., 2018).

Addressing Barriers to Early Help-Seeking and Diagnosis

As mentioned in the former chapters, people living with dementia experience high burdens of disability and dependence on their carers (Aranda et al., 2021; Feast et al., 2016; Lindeza et al., 2020). Underdiagnosis has been associated with social and self-stigma (Nguyen & Li, 2020), inability of people with impaired cognition to recognise symptoms (Harwood et al., 2000), general practitioners (GPs) lacking confidence in diagnosing dementia (Phillips et al., 2012), fear held by people with impaired cognition of the consequence of diagnosis (Page et al., 2019) and, a lack of culturally appropriate diagnostic tools (Nielsen & Jørgensen, 2020). The projection is that by 2050, more than two million people in the UK will be living with dementia (Prince et al., 2014). Therefore, it is one of the most significant public health challenges in Western society (Skov et al., 2022). PAC offers a pathway to counter these barriers by helping individuals understand the diagnostic journey and fostering openness about dementia. However, the effectiveness of PAC may vary significantly depending on how it is communicated and tailored to meet the unique needs of people with dementia. In this chapter, healthcare professionals' insights into how they tailor PAC delivery and address patient hesitations will provide valuable knowledge on the practical and clinical aspects of PAC that contribute to effective dementia care.

Approximately 60 percent of people who experience memory concerns delay seeking help and 25 percent wait more than six months before speaking to a healthcare professional about their perceived problems (Alzheimer's Society, 2019). It is usual for people experiencing cognitive decline to confide first in family members about their concerns, but the fear of dementia remains a significant deterrent to help-seeking (Yun & Maxfield, 2020; Prince et al., 2011). Avoidance of professional help-seeking in the early stages of dementia is problematic as the literature suggests that both people with dementia and those who care for them benefit most from early diagnosis (Clare et al., 2014; Koch & Iliffe, 2010). Such benefits include enabling carers the opportunity to adapt to the changes that characterise dementia and to their newfound role, as well as the ability to access interventions to protect well-being and enable self-efficacy of people with dementia (De Vugt & Verhey, 2013). For individuals experiencing cognitive decline, early diagnosis explains experienced symptoms. It provides access to appropriate services, which can support them in feeling a sense of agency over their diagnosis and increase their quality of life (Rasmussen & Langerman, 2019).

One way to potentially increase help-seeking and possibly diagnosis at an early stage of dementia is to offer PAC within the dementia care pathway (La Fontaine et al., 2014). Within the PAC appointment, the typical approach includes explaining what to expect from the process of diagnosis along with the potential outcomes of an assessment. Its goal is to reduce reluctance towards undergoing an assessment by discussing fears, concerns and misunderstandings of dementia and enabling patient empowerment where the person experiencing cognitive decline can make considerably more informed decisions. Yet, the diverse ways in which PAC is implemented raise questions about its consistency and effectiveness. Insights from professionals who deliver PAC may reveal the practical adjustments necessary to ensure that PAC becomes an effective standardised practice in dementia care.

The PAC appointment is best situated following a GP referral to a memory clinic and the assessment for dementia taking place. GPs are not best placed to deliver the PAC appointment owing to the significant demands already placed upon their time (Konrad et al., 2010). Rather, it would be more suitable to have these appointments conducted by specialists who have a more in-depth knowledge of dementia. PAC aims to explain the dementia diagnosis process, covering the types of assessments, diagnosis delivery, and post-diagnostic services available for both people with dementia and carers. It also addresses previous experiences of dementia and works towards reducing stigma (La Fontaine et al., 2014). These steps must occur before an assessment to ensure truly informed consent for proceeding to the next stage of the diagnosis journey.

Contextualising the Importance of PAC as a Standardised Practice

Exploring these implications enables a person with dementia to make a decision on whether to pursue an assessment (La Fontaine et al., 2014). Placing the person with dementia at the centre of this decision is essential given the significant social and psychological adjustment required upon receiving a diagnosis of dementia for both the person experiencing cognitive decline as well as their families (Lecouturier et al., 2008). Research indicates that anxiety towards a potential dementia diagnosis is decreased when people with cognitive deficits are provided with informal feedback prior to formal disclosure, as conversations around potential diagnoses are considered helpful by alleviating shock should dementia be confirmed (Carpenter et al., 2008). However, access to PAC is not universal, even within healthcare settings in the same country. All memory assessment services across the UK will perform a clinical check – patients do not generally enter the service and dive into a cognitive assessment without some form of discussion taking place first where they may be asked about their sleep hygiene, alcohol intake, any disinhibited behaviours noticed, what difficulties they have experienced, for example (Shukla, 2003). The person with dementia is then asked if they are okay to proceed with the assessment following what could be a 10-minute conversation and this could be argued as a form of PAC. However, if all people with dementia go through this and yet a confirmed diagnosis of dementia still comes as a shock, then it can also be argued that this form of PAC is ineffective. As has been noted in Chapter 3, PAC can be something that is significantly more useful to a person with dementia and those that care for them by creating a conversational and informative space. Further evaluation of services that do provide PAC is needed to encourage its implementation across all early dementia services, and this is what this study seeks to do.

The Present Study

As clinical research continues to evolve, the findings and outcomes from such studies should inform and refine clinical practices, ultimately leading to improved patient outcomes. PAC is acknowledged as beneficial in dementia care (La Fontaine et al., 2014), yet the lack of empirical evidence regarding its mechanisms and effectiveness hinders the development of standardised protocols. This is evidenced further by the few studies available for inclusion in the systematic review that formed Chapter 2. Thus, this chapter seeks to address this gap by exploring the healthcare professionals' perspectives on PAC's strengths, limitations, and impact in practice. These insights may help shape more effective PAC protocols, ensuring that people with dementia and carers across settings receive consistent and supportive care.

This study aimed to investigate the experiential and contextual factors surrounding PAC delivery through semi-structured interviews with healthcare professionals who regularly deliver PAC in dementia care pathways. In line with the study's focus on capturing the shared experiences and nuanced perspectives of healthcare professionals, Reflexive Thematic Analysis (Braun & Clarke, 2022) was selected as an appropriate method. Reflexive Thematic Analysis was used to analyse the data as opposed to traditional Thematic Analysis, as it is used to analyse complex social experiences owing to its theoretical flexibility and reflexivity being a core component of the analytic process, enabling a more credible analysis (Braun & Clarke, 2022). This supports a nuanced understanding of socially constructed health attitudes and enables the identification of broader, collective themes across participants' experiences. Furthermore, reflexive thematic analysis's emphasis on researcher reflexivity allows for an analysis that acknowledges the researcher's interpretive role, making it a valuable tool for exploring the multi-layered dynamics of PAC in dementia care.

Method

Setting

The setting was a National Health Service (NHS) Trust. NHS Trusts are subject to legislation depending upon the country within which they are located in the UK. This study liaised with the Early Intervention Dementia Service team based within a West Midlands NHS Trust in England. This service was purposively selected due to its implementation of PAC, which is not yet standard practice across NHS memory services, despite growing evidence of its benefits for people with dementia, their carers, and healthcare professionals. One of the supervisory team had previously worked as a clinical psychologist within the service and was aware that PAC was actively and routinely delivered there. Following an introduction facilitated through this professional link, the clinical team expressed a willingness to collaborate and support the research. This collaboration enabled access to a site where PAC was already embedded, providing a valuable opportunity to examine the intervention in practice and collect relevant qualitative data. In the UK, government-funded care is organised into different levels. Primary care is usually the first point of contact for people needing healthcare and is most commonly provided by general practitioners (GPs). Secondary care includes services such as the memory assessment service, which requires a referral from a GP to access (Alzheimer's Research UK, 2023). Therefore, GPs are often the first healthcare professionals individuals approach when there is a concern surrounding cognitive decline, seeking support and answers to symptoms (Phillipson et al., 2015). In the UK, GPs commonly conduct brief cognitive screening and refer suspected cases of dementia to memory assessment services or clinics staffed by specialist dementia healthcare professionals, such as psychologists, nurses, psychiatrists and occupational therapists. Following referral, a clinical assessment typically precedes cognitive testing. This clinical assessment phase is particularly conducive to delivering PAC, given its requirement for informed consent from individuals suspected of being in the early stages of dementia to proceed with cognitive assessments.

Study design

This study used Reflexive Thematic Analysis (RTA; Braun & Clarke, 2022) to explore the role of PAC within the complex nature of the dementia diagnosis journey. It enabled an in-depth exploration of healthcare professionals' views and experiences regarding PAC delivery. As previously mentioned, Reflexive Thematic Analysis's flexibility and reflexivity make it an excellent method to capture the socially constructed perspectives from PAC appointments. By encouraging critical reflection on researcher assumptions and interpretations, RTA promotes a deeper understanding of the data and enhances the rigour of findings (Campbell et al., 2021). This method allows for the identification and iterative refinement of patterns or themes, shedding light on the underlying processes that influence PAC's role in dementia care.

To mitigate any potential issues in coding to theme development, the research team held frequent discussions. The research team consisted of myself and four academic supervisors with expertise in cognitive ageing, neuropsychology, health inequalities, and cultural psychology. Dr Stephen Badham, my Director of Studies, is an expert in healthy cognitive ageing and has published widely on memory in older adults, including work with clinical populations. Dr Anna Buckell is a practising clinical neuropsychologist and previously worked within the Early Intervention Dementia Service in Worcestershire, which was the setting for this project. Dr Miriam Sang-Ah Park is a social and cross-cultural psychologist whose research examines the links between culture, society, and the individual, particularly in relation to sociopolitical change and identity. Dr Beth Jones specialises in health inequalities and the development of interventions to support marginalised groups, and has collaborated with NHS services to develop tools for evaluating patient outcomes. All team members were involved in shaping the design and methodology of the study, and their combined expertise informed both the data collection and analysis phases. Some of the issues encountered within the analysis included theme development where some of the themes that had been identified overlapped or were summaries that were presented as theme titles. Through regular meetings the research team assisted in refining them and assisted in creating themes that were reflective of the healthcare professionals' experiences. In this way, the potential biases in interpreting what participants were saying was reduced and the reliability of the results was increased.

This study adopted a realist ontological standpoint. This means that within the experiences of healthcare professionals' experiences of PAC, there exists an objective reality (Jenkins, 2010). Furthermore, it acknowledges that people understand these experiences from former social interactions and interpretations, and the benefits and challenges of PAC are, therefore, going to be shaped by the contexts of previous PAC appointments experienced by the healthcare professionals. A constructivist epistemology complements this ontological stance by emphasising that knowledge is co-constructed through interaction and shaped by the context within which it is understood (Packer & Goicoechea, 2000). In this way, the study acknowledges that while healthcare professionals' perspectives reflect real experiences, they are also shaped by social and cultural factors inherent to dementia care.

Throughout the analysis, careful attention was paid to addressing potential sources of bias and reliability concerns, given the interpretative nature of reflexive thematic analysis.

Members of my research team encouraged me to use a reflexive journal throughout the analysis process and note any preconceived ideas to help me mitigate any confirmation bias by reflecting on how these could shape how I interpreted the themes. This approach aligns with the principles of reflexive thematic analysis, which view the researcher's subjectivity as a valuable analytic resource rather than a bias to be eliminated. This reflexive journal assisted in ensuring the validity of the results by highlighting how I, as a researcher, can influence the results of the analysis.

The combination of a realist ontology and constructivist epistemology aligns with the use of reflexive thematic analysis, which allows for an in-depth examination of how shared experiences shape healthcare professionals' understanding of PAC. By adopting this stance, the study aims to capture the broader, collective themes that reflect PAC's role in dementia care while acknowledging the unique, socially constructed nature of each professional's account. This approach enables the goal of the study which is to produce contextually grounded results that have practical implications for delivering PAC.

Though this study used Reflexive Thematic Analysis to capture the perspectives of healthcare professionals, an alternative method, Interpretative Phenomenological Analysis (IPA), was initially considered. However, the qualitative researchers within the research team advised the use of Reflexive Thematic Analysis as IPA focuses on single experiences shared by individuals as opposed to a collection of themes from a wider sample of participants (Noon, 2018). Reflexive thematic analysis, with its flexibility and ability to accommodate diverse perspectives (Braun & Clarke, 2022), was better suited for uncovering common themes across the experiences of healthcare professionals, thus allowing for insights into the collective understanding of PAC's impact.

Reflexive Thematic Analysis integrated the diverse perspectives of healthcare professionals through a multicomponent process. These included getting familiar with the data, generating codes and themes, reviewing, defining and naming themes, report production, and discerning reflexivity and trustworthiness of results (Braun & Clarke, 2021). In doing so, Reflexive Thematic Analysis obtained both individual nuances plus collective insights, providing a more holistic understanding of the healthcare professionals' views of the key components and effectiveness of PAC.

The use of semi-structured interviews was appropriate for several reasons. Firstly, they offered a flexible approach to data collection to explore the participants' perspectives (Adeoye-Olatunde & Olenik, 2021). This flexibility is especially useful for conducting research in something that is as multifaceted as PAC, where delivery is influenced by a multitude of contextual factors. Secondly, using semi-structured interviews to collect data enables unexpected insights to develop (Wolff et al., 2019), enabling the interviewer to probe further and ask questions around these, resulting in richer, nuanced data. Such was the case in this study, where the participants were made to feel comfortable to talk freely about their views and experiences of delivering PAC.

Participants

Participants were recruited using purposive sampling to ensure that those involved had direct experience delivering PAC within the memory service. Inclusion criteria required participants to be healthcare professionals employed within the Early Intervention for Dementia Service (EIDS) in the West Midlands, UK, who regularly delivered PAC to people with dementia and their carers or families. Exclusion criteria included individuals who had not personally conducted PAC sessions or who were employed in non-clinical roles. A total of 17 healthcare professionals were invited to participate via email to the wider team; however, five were deemed ineligible as they did not deliver PAC as part of their usual care. Of the 12 eligible individuals, 10 agreed to participate and completed the interview, while two chose to withdraw prior to data collection. This sampling approach enabled the collection of rich, practice-based insights into the implementation and effectiveness of PAC from those with direct clinical experience.

Interview schedule

A member of the research team, who was formerly a healthcare professional in the EIDS team, contributed their clinical knowledge to help guide the development of the interview questions. Drawing on findings from a prior service evaluation conducted within the team, we collaboratively refined the interview schedule by exchanging drafts until agreement was reached. The finalised schedule was shared with the current EIDS team to invite additional input, although no further changes were requested. Healthcare professionals were then invited to participate in semi-structured interviews, using a flexible guide designed to encourage open discussion (Phillipowsky, 2020). These interviews explored healthcare professionals' perspectives on the benefits and challenges of delivering PAC, following an interview guide comprising 11 open-ended questions (see Table 7).

Procedure

Nottingham Trent University and the Worcestershire and Herefordshire Health and Care NHS Trust obtained favourable ethical approval for the study. Healthcare professionals who expressed interest in the study contacted me, after which they received a participant information sheet and consent form. After the signed consent form was returned, healthcare professionals received a copy of the discussion topics for the semi-structured interview ahead of time. This action was intended to ensure the questions were suitable and to provide them with the opportunity to think about their answers. Interviews took place using Microsoft Teams where they were recorded and transcribed, each lasting up to 60 minutes. Microsoft Teams was used owing to the geographical location of myself and of the healthcare professionals, however, there is an emerging trend to use technology in this way for conducting qualitative interviews (Lobe et al., 2020). The use of Microsoft Teams also made participation significantly easier for the healthcare professionals as it enabled an accessible and convenient way to engage with the study and potentially widen participation (Lobe et al., 2020).

Nassaji (2015) also notes that despite physical distance, using video conferencing enables rich data collection if participants are familiar and trusting of the programme being used. Another benefit is the time and resources that are saved as no travel costs are incurred which means that they are a useful low-cost option for researchers (Khan & MacEachen, 2022). The healthcare professionals were encouraged to locate a private and comfortable space for the interview to enable candid and open discussions. The interviews took place from March to May 2023. Table 8 details how the analysis steps were followed and highlights the reflexivity and trustworthiness in the analytic process. Initial coding was conducted independently by the lead researcher using NVivo software. Following this, preliminary themes were generated and developed through multiple rounds of iterative analysis. A member of the supervisory team, who has extensive experience in reflexive thematic analysis, was closely involved in reviewing and shaping the evolving thematic framework. Subsequent versions of the themes and supporting extracts were shared with the wider research team, whose feedback contributed to further refinement and clarification. This collaborative process enhanced the rigour of the analysis by supporting reflexive interpretation and ensuring that the final themes were both analytically coherent and grounded in the data. No demographic details were gathered since the healthcare professionals were sourced from the same service, which could risk compromising anonymity. Rich and detailed accounts were provided by the healthcare professionals, resulting in common themes that sufficiently addressed the study's objective and questions.

Data analysis

The interviews were transcribed using NVivo software. Reflexive Thematic Analysis (RTA; Braun & Clarke, 2021) was used in conjunction with a constructivist epistemological approach to understand the experiences of healthcare professionals delivering PAC. This study adopted a constructivist stance, viewing knowledge as something co-created through social interactions, shaped by cultural, contextual, and relational factors (Amineh & Asl, 2015). This perspective directed the analysis towards comprehending the participants' views and experiences not as definitive truths, but as situated, socially influenced understandings. Adopting a constructivist approach allowed for a nuanced exploration of how healthcare professionals perceive and implement PAC, prioritising their unique insights to inform practice and service development in dementia care.

Positionality was carefully considered throughout the study. I have experience working in a memory assessment clinic that did not implement PAC, and the researcher who helped to construct the interview questions previously worked in the Early Intervention Dementia Service where participants were recruited. To mitigate potential bias, every effort was made to use open-ended, neutral, and assumption-free questions, encourage detailed responses, practise active listening, and prepare the interview schedule in advance. Reflexive journaling was maintained throughout data collection and analysis to support critical reflection and enhance the rigour of the study.

The initial coding phase was conducted inductively at a semantic level, meaning codes were closely linked to the explicit content of the data without imposing preconceived theoretical ideas. Coding was conducted manually using NVivo, with each transcript examined line-by-line to identify meaningful features relevant to the research question. Coding was iterative, with multiple passes through the data to ensure depth and consistency.

Following initial coding, codes were grouped into candidate themes based on shared meaning and conceptual connections. Preliminary themes were presented and discussed within regular research team meetings. Feedback from the supervisory team, who brought expertise in qualitative methods and dementia care, supported the refinement of themes to ensure coherence, distinctiveness, and grounding in the data. This collaborative approach encouraged reflexivity and challenged potential individual biases in interpretation.

The final phase involved reviewing and defining the themes by systematically revisiting the coded extracts and original transcripts, ensuring that each theme captured a strong, coherent pattern of meaning. The iterative and team-based nature of this process enhanced the trustworthiness and credibility of the analysis, supporting the production of findings that authentically reflected participants' shared and diverse experiences of delivering PAC.

Table 7

Questions used during the semi-structured interviews held with healthcare professionals

Interview Questions
What is your understanding of pre-assessment counselling? (*Prompt: How would you define pre-assessment counselling to someone?)*
What does pre-assessment counselling involve? (*Prompt: What does pre-assessment counselling consist of in your service? What should pre-assessment counselling involve? Describe your involvement with pre-assessment in your role?*
Could you tell me about the impact pre-assessment counselling has on a service user and their families? (*Prompt: What are the benefits to patients? What are the challenges to patients? Describe the experience patients normally have with pre-assessment counselling.*
What impact does PAC have upon staff and services? *(Prompt: In the immediate sense? In the future?)*

Could you tell me about your role within this service? (*Prompt: what does your role involve? What kind of activities do you do in this role day to day? How long have you been working in the team for?*)

What would you say the signs of quality are in PAC? *(Prompt: What must PAC always include and why?)*

What are your views with regards to whether PAC supports a timely diagnosis? *(Prompt: How does this differ to 'quick diagnosis?')*

How do you manage the different expectations or agendas within the PAC appointment? *(Prompt: What kind of expectations does the person with dementia tend to have? The carer tends to have? You tend to have?)*

How do you manage the balance of remaining sensitive to service user fears and anxieties whilst being open in dialogue? *(Prompt: Have there ever been times where this balance has been especially difficult to maintain? How did you bring the balance back?)*

What kind of training or guidance would all staff need to have delivered to ensure excellent PAC provision? (*Prompt: What universal or mandatory training must you do before you can deliver PAC? Do you have a handbook/framework which you can refer back to for reference?)*

Is anything else that is significant to you or anything, we have not covered that you would like to add about your experience of pre-assessment counselling or anything which we have not covered that is really important to you around the topic of pre-assessment counselling.

Reflexive statement

This study aimed to comprehensively explore the impact of PAC within the dementia diagnostic journey, an area requiring sensitive and nuanced investigation. A member of the research team who had previously worked within the EIDS team supported participant recruitment, which may have positively influenced participation. Additionally, my own prior experience of working in a memory assessment service shaped my understanding of the clinical context. To minimise potential bias, I maintained a reflexive journal throughout data collection and analysis, recording reflections on how my background might influence interpretation. This reflective practice supported transparency and helped ensure that theme generation remained grounded in participants' accounts rather than personal assumptions.

Table 8

Six Steps of Reflexive Thematic Analysis (Braun & Clarke, 2021)

Steps	Description
Familiarising with the data	To gain a deeper understanding of the data, I began by thoroughly reviewing the complete transcripts and field notes. While doing so, I recorded observations and reflective comments in a structured manner.
Generating initial codes	Following this, I started coding the transcripts inductively.
Generating themes	After I had completed 4 rounds of coding, I developed some initial themes and then collaborated with another member of the research team who has extensive expertise in reflexive thematic analysis.
Reviewing themes	This process required iterative engagement with the raw data and the codes which led to a consensus across the whole of the research team on the themes that were subsequently derived and the patterns that connected them.
Defining and naming themes	Myself and two qualitative members of the research team assisted in reviewing the themes and ensuring that the quotes I had selected were appropriate in supporting the findings.
Producing the report	The collaboration resulted in this chapter, a comprehensive report which has incorporated carefully considered quotes that illustrate key points.
Reflexivity and trustworthiness	The expertise of the research team coupled with our reflexive approach has enabled us to identify patterns within the raw data early on in the process, especially concerning the challenges that healthcare professionals face. Furthermore, reflexivity has helped me to critically evaluate some of the assumptions I held surrounding PAC, how it is implemented and its content to meet patient needs. Lastly, iterative

	rounds of coding as well as conversations concerning themes and the interpretation of the themes contributed to the rigour of the study.

Results

A comprehensive coding and analysis process revealed three themes which are illustrated in Table 9. All participant names used in this thesis are pseudonyms, assigned to protect anonymity while preserving the narrative quality of their accounts.

Table 9

Emergent themes and subthemes from analysis

Theme	Subtheme
1. The person with dementia is central in their diagnosis journey	1a. Timely diagnosis is important for the wellbeing of people with dementia
	1b. Empowering patients in the diagnostic journey
2. Candid conversations build strong therapeutic alliances	
3. People with dementia learn to accept that a diagnosis does not define them or their lives	3a. Fostering resilience through comprehensive support
	3b. People with dementia understand that it is possible to live well with dementia and retain their lifestyle

Theme 1: The Person with Dementia is central in their diagnosis journey

Healthcare professionals noted specific challenges such as inconsistent patient-centred practices and premature diagnostic pressure from where assessment and diagnoses are given before the person with dementia is ready. This emphasis placed upon the agency that a person with dementia has in terms of timing and pace demonstrates patient-centred approaches as being especially important. This first theme highlights how PAC is viewed as essential to the dementia care pathway in facilitating timely diagnoses that are respectful of autonomy in contrast to those that are rushed and fail to respond to individual needs and wishes.

Subtheme 1a. Timely diagnosis is important for the wellbeing of people with dementia.

The role that PAC has in enabling diagnoses that prioritise the well-being of people with dementia was repeatedly discussed by the healthcare professionals, and that this was facilitated through timely diagnoses as compared with quick ones, by ensuring that the wishes of the person with dementia are centrally placed within their care. In contrast, the latter prioritises the interests of stakeholders.

> *"I think PAC definitely supports timely diagnoses, but I also think it depends on whether you are interested in what is best for the individual or what is best for the Trust! [...] it's making sure that the person is ready to hear it in the right frame of mind. Essentially, timely diagnoses are person-centred. Quick diagnoses aren't." Ash.*

Ash's perspective initiates the discussion by highlighting the significance of timely diagnoses in the context of PAC. They highlight how timely diagnoses prioritise the individual's well-being, contrasting with rushed diagnoses that may overlook these considerations. This provides the foundation to explore how PAC affects the emotional wellbeing of people with dementia and how it enables timely diagnoses. Charlie shares Ash's regard of person-centred care and expands upon this by discussing the importance of journeying at the pace of the person with dementia, as well as highlighting the practical effects of making individual readiness for diagnosis a priority.

> *"Working at their pace is quite important. You know, we always ask for a timely… timely diagnosis… timely to me is when they're ready, not when we are. And… and I get that we have to diagnose people and move on and get all these rates up - I do get*

> *that, but I think if we're forcing somebody through a system that's scared that's worried, doesn't understand it… they're gonna retract and we, we're not gonna engage. And it's fearful. It's horrible for them." Charlie.*

Charlie believes that it is more important to work with the patient at their pace and arrive at a diagnosis in their own time and that in doing this, PAC helps to support the emotional well-being of people with dementia throughout the diagnosis journey. Morgan adds to Charlie's perspective by discussing where mistakes had previously been made and how hastening diagnosis has the potential to do harm.

> *"And you know, we made mistakes. […] we've encouraged people to go along with it, when perhaps they weren't ready. And I think we did harm to people. You know, you can do harm to people." Morgan*

Morgan's view of causing harm urges a critical reflection on former practice. It shows that dementia diagnoses need to be delivered at a time that is right for the person with dementia, being mindful of their emotional state, which is enabled through the person-centred approach that PAC takes. Jules feels that people with dementia are best supported when they are given the time to process information and determine for themselves how to proceed. This demonstrates that the person-centred approach that PAC takes helps people with dementia to be confident that whatever decision they arrive at will be the one that works best for them, mitigating psychological harm and improving well-being.

> *"Yeah, I had a lady who sort of said she wanted to move forward with assessment. Then she got quite upset at the end of PAC and the family did want it to move forward with assessment. And I just gave time, and I did explain, you know, the benefits of the early diagnosis again at the end of the…, you know, at the end of my actual initial appointment. And… And I gave her some time and I always say to people it's not even a decision you got to make now. I can go away and give you a phone call or I can come back out and see you in a week's time. You can have a bit of time to digest what I've said, and I could go through things again with you." Jules*

Jules reveals how the provision of time to people with dementia to process information and formulate decisions as to if and how they wish to move forward helps them to feel supported and empowered. In summary, this subtheme discusses the importance of clinical practice in protecting the well-being of people with dementia and that this is most effectively achieved through delivering sensitive information at a pace determined by the person living with dementia. The healthcare professionals participating in this study view PAC as something that enables timely dementia diagnoses as opposed to quick ones, the latter of which have the potential to induce psychological harm by overlooking the individual needs and care wishes of people with dementia.

Subtheme 1lb. Empowering patients in the diagnostic journey.

The healthcare professionals discussed the importance of people with dementia feeling that they had control over their diagnosis journey and how PAC can empower them by supporting them in doing this. Because PAC enables people with dementia to make decisions at a time that works for them, their well-being is subsequently improved, thereby re-establishing their feelings of control.

> *"I think having that choice is really important because you know, especially with something like a dementia, you know, often people aren't able to make choices in the later stages. So, giving people that power, giving people that sense of control and return that agency to them is really important, really, really important." Ash*

Ash's interpretation emphasises the ethical imperative of empowering patients in decision-making processes, particularly in contexts where cognitive decline may limit their ability to exercise autonomy. Morgan continues by explaining the importance of the person with dementia being able to make decisions in the diagnosis journey in support of this.

> *"So yeah, I'll reiterate the importance of this being patient choice. There's no right or wrong decision. It's their decision. And you know, and 'I can walk out this door today [PAC is typically delivered in people with dementia's homes] and if you don't want to see me again, then that's absolutely fine'." Morgan*

Morgan states that it is important that people with dementia have their choices and views respected and how this enables an environment to support decision-making. Morgan recognises that a person in the early stages of dementia has the right to refuse assessment and provides reassurance that they are free to terminate the PAC appointment and any subsequent appointments and assessments that they would encounter on the diagnosis journey. Morgan's views on supporting patient choice are echoed by Charlie, who illustrates how this applies practically in terms of ensuring that the needs and wishes of people with dementia are prioritised over external influences.

> *"And I just have to be honest with the family. 'I'm really sorry, but this is mum's assessment. And I'll take your points. They are very valid. I appreciate your worries, but this is about mum and what she wants'." Charlie*

Charlie demonstrates the necessity for setting boundaries and clear communication in PAC and ensuring that the decisions being made concerning the diagnosis journey are being led by the person with dementia and their preferences as opposed to being driven by external pressure. Jules shares a similar view on clear communication and patient-centred decision-making and discusses the significance of ensuring that people with dementia and their families receive comprehensive information to ensure informed decisions.

> *"…they can then make an informed decision about whether they want to move forward or not. They can't make that informed decision if you've not given them all the information." Jules*

Jules reinforces the theme of autonomy by stressing the importance of comprehensive information provision to ensure informed decisions are made that benefit the person with dementia. By recognising the role of healthcare professionals in facilitating patient understanding and autonomy through transparent communication, this interpretation highlights the ethical responsibility to empower patients to engage actively in their healthcare decisions.

Empowering people with dementia to decide the timing and pace of their diagnostic journey fosters open dialogue. PAC enables a safe space where people with dementia feel empowered to talk about any fears or concerns, or cognitive changes that they have noticed, and the healthcare professional conducting the appointment can reassure them that they will proceed to a dementia assessment only if the patient should choose to. However, many people with dementia appreciate the opportunity to discuss this with those who would support them through the diagnosis journey and beyond. Such conversations enable self-determination, dignity and trust in the relationships between people with dementia and the healthcare professional, empowering individuals with knowledge and control for personalised care.

Theme 2: Candid Conversations Build Strong Therapeutic Alliances

Healthcare professionals repeatedly mentioned the significance of holding open and honest conversations with people with dementia and their carers and that this was an essential component to PAC. Each participant stressed how candid conversations led to trusting interactions that enabled strong therapeutic alliances.

> *"Definitely people trust you more as well. There's less of that kind of guarded feeling, and yeah, I just think it's better all round for everybody. People feel that they can tell you more because you've been up front with them. I just… I think it works really well." Ash*

Ash feels that PAC is particularly valuable in that trust is built through candid conversations. This trust is essential for forming therapeutic alliances between healthcare professionals and people with dementia and their carers. Kit agrees that this is the best way to build trust and expands on how transparent communication is required to dispel stigma and manage expectations.

> *'...you have to be very clear. You have to let people know what it is about, and you cannot just sugar coat it or… or whatever, because that's misleading the person and disrespectful. The fact that we've got the word dementia in our title [Early Intervention Dementia Service], I think really helps.' Kit*

Kit's perspective reinforces the theme of honesty and openness in PAC, emphasising how it helps set realistic expectations and confront stigma. By using clear language and avoiding euphemisms, healthcare professionals aim to provide individuals with realistic expectations and prepare them for the diagnostic journey ahead, thus promoting informed decision-making and reducing anxiety. Stacy also highlights the role of open, honest, and transparent conversations in creating a supportive environment for discussing dementia diagnosis.

> *"You're starting off a process by being very open, honest, transparent about the purpose of… of the appointment when you… when you go out and see somebody. There's no kind of hiding or talking in terms of memory problems or, um, cognitive difficulties or other terms that… that we sometimes use. I think it's just an… an openness really, about kind of opening that conversation around dementia and your*

> *patients are kinda given the floor to discuss their views, their thoughts and feelings." Stacy*

Stacy perceives the role of patient-centred care and clear communication to be imperative in PAC as it creates a safe and supportive environment where people with dementia feel empowered to lead the discussion of their diagnosis journey. Healthcare professionals seek to establish a partnership with people with dementia and their carers, aiming to inform and support them appropriately in accordance with their needs, which ultimately enhances the quality of care provision. Jules agrees with Stacy but proceeds to mention how the media and internet searching can impact upon the understanding of dementia and why managing expectations is critical.

> *"I think some, you know, some people have Googled the thing to death, haven't they? Before you've gone to Doctor Google, which has a lot to answer for. So, and especially with the new medications being spoken about recently on… on you know, on the television, that it's some magic cure, and they think that things are gonna be sort of ready to be prescribed within, you know, a month or so. And we have to be honest about that, that it's actually not and that it doesn't work for everybody and it's not for every type of dementia." Jules*

Jules discusses how moderating misconceptions and expectations towards potential treatments for dementia is critical during the PAC appointment. Through honest information provision, the healthcare professionals who deliver PAC endeavour to empower people with dementia to make decisions concerning their healthcare. Jules's emphasis on combating stigma and promoting transparency is echoed by Morgan, who discusses the importance of using clear language and advocating for openness from the outset of the diagnostic process.

> *"I think when the… when the patient receives our letter and then our… our title is at the top, I think that's also at the start of things. You know, it's that using that word, you know. By not using it, I think we're almost colluding with the stigma around it. Let's get it out there, let's be open, let's be honest, right, right from the beginning, before we even walk through the door about what… what we're about, what we're doing." Morgan*

Using clear language such as "dementia" in communication materials, healthcare professionals advocate for transparency and honesty, thus fostering a supportive environment for patients and their families throughout the diagnostic journey. Candid conversations are considered an important component of PAC as the person with dementia not only forms trusting relationships with the healthcare professionals conducting it, but they also ensure that any myths and misconceptions of the condition are removed and expectations are managed concerning the dementia journey.

Theme 3: People with dementia learn to accept that a diagnosis does not define them or their lives

Healthcare professionals mentioned that the PAC appointment is critical in empowering both people with dementia and their carers with knowledge and coping strategies. This support helps them to navigate the challenges of dementia while optimising their QoL and preserving their sense of identity and purpose.

Subtheme 3a. Fostering resilience through comprehensive support.

The PAC appointment is crucial for providing essential information to people with dementia and their carers and dispelling misconceptions. It demonstrates that a diagnosis of dementia is not the end but the beginning of a new journey and that appropriate support and resources are available.

> *"...quality of life is a little bit better when you know what you're dealing with. Um, and in particular for families knowing what support's out there and when to get it and who to get it from. And you know, because there's things out there for them. Not just talk to Doctor Google." Jules*

According to Jules, it is apparent that QoL is enhanced through PAC, and this is one of the primary benefits of PAC appointments. PAC enables people with dementia and their carers to confidently progress with their diagnosis journey when provided with comprehensive information about what to expect. This highlights the usefulness of PAC in reducing fears and concerns and improving QoL for people with dementia and those who care for them. Like Jules, Jan notes why it is important to understand the unique needs of people with dementia and how this leads to individualised support and care, adding to what has already been found regarding the collaborative nature of PAC discussions.

> *"You've got to take the time to understand the person, what their needs are really and finding out from their point of view what they would like to happen. [Also], what support they think they need, what's within your remit, [and] what you're able to do. And if you're not [able to do something] who they can contact to be able to gain that information." Jan*

QoL of people with dementia and carers increases when healthcare professionals provide care and support tailored to individual needs, resulting in more informed decision-making. Ash agrees with Jan in that collaborative PAC appointments lead to continued support and discussion following the initial appointment. Ash notes how PAC is essential in the long-term for people with dementia and their carers.

> *"And we'll say, you know, we've got lots of resources, lots of organisational support in the local area for you and, you know, it's about living your life as well, so if things do change then you know where to go for support and everybody has an allocated OT [occupational therapist] or nurse, so there's always somebody that you can contact to talk to." Ash*

PAC appears to enable QoL through structured support and informed decisions. Although PAC is considered to be an essential tool for equipping people with dementia and their carers with resources and knowledge, access to ongoing support is essential to preserve and sustain QoL long-term. Morgan notes the advantages that proactive management can have on outcomes for people with dementia and those who care for them.

> *"I'll say something along the lines of... and, you know, the feeling nowadays is the earlier that you intervene with conditions like the dementia, the better your future can be. Forewarned is forearmed. You know, if you know early on that there's something changing, then it can give you and your family the opportunity to understand it, to learn about it." Morgan.*

Morgan demonstrates how healthcare professionals can promote proactive management and how this can impact long-term well-being when dementia is diagnosed early on and interventions are explored. PAC helps to enable this by fostering resilience in people with dementia, which improves QoL, as noted in the comment that to be forewarned is to be forearmed.

In summary, healthcare professionals perceive the PAC appointment as an important tool for information and support provision where they reduce stigma by dispelling misconceptions about dementia and instead attempt to instil hope. They discuss how comprehensive information and continued discussions following the PAC appointment are important for reducing fear of dementia and improving QoL. Tailored conversations held in PAC aim to provide the person with dementia with confidence to navigate the diagnosis journey. Essentially, PAC is thought to be invaluable in the care continuum by enabling informed choices and sustained QoL.

Subtheme 3b. People with dementia understand that it is possible to live well with dementia and maintain their lifestyle.

Previous literature has found that stigma and misconceptions of dementia lead to fear of the condition (Yun & Maxfield, 2020). The healthcare professionals noted that whilst challenges can accompany a diagnosis of dementia, it is possible to live well and reduce the levels of fear should dementia be confirmed. Further to this, they emphasise that with support and possibly adaptation, people with dementia can maintain their lifestyles that contribute to enhanced well-being.

> *“So, it… it’s talking to people about that… there’s lots of people that live very well with dementia and, you know, still drive, you know, and carry on with activities, still enjoy life and, you know, good relationships. And so, I think it’s, you know, highlighting that to people, yeah. […] You talk to them about the support, the interventions that can be put in place and… and, you know, support people to live well.” Jamie*

Jamie notes that many people with dementia continue to live meaningful and fulfilling lives after receiving a diagnosis, which demonstrates the requirement of balancing conversations concerning challenges with opportunities for intervention and support. Kit adds to this concept by discussing how PAC helps to promote realistic expectations while providing hope for people living with dementia and those who care for them.

> *“We inform patients about the service to increase their knowledge about dementia. To start the conversation about the interventions they can receive, which way may improve the quality of life with diagnosis of dementia, the support they and their*

> *family can receive. And I suppose, the best of it is that… kind of… I'm not saying you can have a positive outlook from pre assessment counselling but almost to have a little ray of hope that perhaps the situation may not be as bad as they imagined." Kit*

Kit endeavours to foster hope and optimism by informing people with dementia and their carers about potential interventions and support services. The PAC appointment helps to create the space for fears and concerns to be heard, listened to, processed and addressed which contributes to the psychological adjustment that is required upon receiving a diagnosis of dementia. QoL is maintained and a sense of identity and agency are enabled by constructing realistic expectations of the dementia journey from the assessment through to diagnosis and the support and interventions available beyond. In this way, people with dementia are provided with realistic hopes and expectations and Pat discusses this further, noting the importance of maintaining a sense of normality and optimism through practical support.

> *"The ultimate is to make things better, you know, and to hope that what comes out is that quality of life stays the same and it doesn't dip and it doesn't… Yeah, okay, there might be the diagnosed dementia, but we can live well with it." Pat*

Pat does not suggest that a diagnosis will not come with challenges but that PAC promotes positivity and stability and that this is important to maintain QoL. Ash provides additional insights that build upon Pat's views on supporting people with dementia. These enhance the aim of providing hope and empowerment to people with dementia by recognising the challenges that may lie ahead while stressing the practical strategies and support resources available.

> *"We talk about how it is possible to live well with dementia too even though it may come with challenges. However, there are lots of practical strategies and lots and lots of resources to live well with dementia. Lots of resources for onward support." Ash*

By acknowledging potential future challenges whilst emphasising the abundance of resources that are available to people with dementia and their carers at all stages of the dementia journey, Ash bolsters the message of hope and optimism discussed in former quotes. Misconceptions of dementia and stigma are a source of fear for people experiencing cognitive decline. However, healthcare professionals seek to address these potential barriers to diagnosis within the PAC appointment and aim to instil the hopeful concept that it is possible to live well with dementia. Healthcare professionals can offer interventions and support and signpost and refer to appropriate services as a result of a PAC appointment, which in turn reduces fear of dementia and encourages a sense of hope whilst enabling a person with dementia and those who care for them to overcome potential challenges resulting in maintaining fulfilling lives through knowledge and coping strategies.

Discussion

The aim of this study was to explore the perspectives of healthcare professionals who deliver PAC and the experiential and contextual factors surrounding PAC and its strengths, limitations and impact in practice upon people who live with dementia. The questions that shaped and guided this study explored the importance of PAC in enabling timely dementia diagnoses, how people with dementia could be empowered through the implementation of PAC, and what components of PAC contributed to addressing stigma and building trusting relationships in the dementia care pathway. These questions were operationalised in the analysis through reflexive thematic analysis, and findings were conceptualised into three themes, namely: (1) The person with dementia is central in their diagnosis journey, (2) Candid conversations build strong therapeutic alliances, and (3) Patients are more than their diagnoses (see Table 9).

The first theme noted that people with dementia are central in their diagnosis journey. Specifically, that timely diagnosis is important for the well-being of people with dementia (Prince et al., 2011) and that patients are empowered in the diagnostic journey (Merl et al., 2022). The healthcare professionals who took part in this study discussed that timely diagnoses were imperative to the well-being of people with dementia but recognised the nuanced nature of dementia journeys. They acknowledged that quick diagnoses fulfil statistical goals but that these should never be prioritised above careful and considered collaborative approaches that placed the person with dementia at the centre of their care and recognised how this conflicted with the push to increase dementia diagnosis rates. Quick diagnoses may result from the plans published by the NHS Commissioning Board in recognising and rewarding practices that take a proactive approach to identifying early signs of dementia which can encourage timely assessments and intervention (NHS Commissioning Board, 2013). Moreover, the findings highlighted the multifaceted impact of diagnosis, highlighting the necessity for healthcare professionals to assess its potential effects on the overall well-being and engagement of the person with dementia in post-diagnostic services. Furthermore, the tensions between the interests held by commissioners and healthcare professionals who sought to prioritise the welfare of people with dementia profoundly suggested that the delivery of PAC appointments needs to strike a delicate balance in its approach. By placing the person with dementia at the centre of their care and acknowledging that people within the early stages of dementia have the capacity to make informed decisions, the healthcare professionals sought to promote autonomy, reduce external pressures and enable communication between people with dementia and their carers which lead to optimal experiences and outcomes in the diagnosis journey.

The findings of this study are consistent with previous research that notes that by focusing on the individual needs of people with dementia and involving them in decisions leads to better outcomes (Clare et al., 2014; Koch & Iliffe, 2010). This research supports the findings of Bunn et al. (2012). It illustrates that timely, tailored interventions are critical in meeting the unique needs of people with dementia, aligning with PAC's goals of reducing stigma and facilitating smoother transitions into diagnostic and support services. By reinforcing the relevance of PAC, this study builds on past research while addressing a gap in understanding PAC's specific impact on dementia care processes.

Additionally, the study illuminated the significance of empowering people with dementia in decision-making processes surrounding diagnosis. Healthcare professionals emphasise the need for patient autonomy, psychological readiness, and familial collaboration in the diagnostic journey. The findings emphasised the importance of acknowledging and restoring agency to people with dementia, particularly in the early stages, to facilitate informed decision-making and improve overall healthcare outcomes (Street et al., 2012). Furthermore, this study found that developing safe spaces where people with dementia could voice their views, needs and preferences was essential to ensure that their voices are heard when it comes to making decisions (Fetherstonhaugh et al., 2013). The assimilation of problematic voices model (Stiles, 2001) appears consistent with the findings of enabling people with dementia by promoting the inclusion and acknowledgement of marginalised voices within healthcare settings. The model notes the significance of recognising the perspectives of patients to feel as though their choices are heard and implemented as much as possible. When applied within PAC, this cultivates environments where agency and empowerment are enabled so that people with dementia direct the discussions and decisions concerning their diagnosis journey. By incorporating the problematic voices model, healthcare professionals can ensure that the voices of people with dementia are prioritised and that the diagnostic processes align with their needs and wishes. This then strengthens and supports the role of people with dementia in the diagnosis journey, where their experience is shaped by inclusivity, respectfulness and patient-centred care.

The second theme found that candid conversations build strong therapeutic alliances. Each healthcare professional who participated in this study discussed the requirement of open, honest and transparent communication within PAC to generate trust and rapport. Communication Accommodation Theory (CAT; Giles & Ogay, 2007) emphasises why adapting communication styles is necessary and how it contributes to feelings of understanding and trust within the triadic relationship. CAT proposes that when healthcare professionals adjust their language, tone and approach to meet the cognitive and emotional needs of people with dementia, it improves patient engagement and understanding, particularly when used in sensitive discussions such as diagnosis (Giles & Ogay, 2007). In PAC, CAT demonstrates the need for clear and compassionate communication, which not only validates patients' experiences but also mitigates feelings of fear and confusion. Through accommodating communication styles, healthcare professionals can reinforce patients' autonomy and foster therapeutic alliances, thereby promoting a more supportive and stigma-free diagnostic environment.

Avoidance of professional help-seeking in the early stages of dementia is problematic, as the literature suggests that both people with dementia and their carers benefit most from early diagnosis (Clare et al., 2014; Koch & Iliffe, 2010). According to the healthcare professionals interviewed in this study, early diagnosis also provides carers with the opportunity to adapt to the changes that characterise dementia and to their evolving role. They described how PAC can help people with dementia access support sooner, understand their symptoms, and begin adjusting emotionally and practically. These insights are consistent with previous literature that highlights early interventions as a way to protect well-being and foster self-efficacy in people with dementia (De Vugt & Verhey, 2013). For individuals experiencing cognitive decline, early diagnosis was described by professionals as a way of offering a meaningful explanation for the challenges they face. Healthcare professionals acknowledge that although they recognised the unease surrounding the topic of 'the D word', they felt that it was important to use the word dementia to not perpetuate stigma as this, coupled with the ambiguity of euphemisms in the diagnosis journey, had the potential to cause psychological harm (Kaduszkiewicz et al., 2008). The healthcare professionals sought to address stigma, misconceptions, fears and anxieties surrounding dementia. They recognised that the feelings and experiences of people with dementia were valid through the candid conversations that governed PAC. Personal experiences of dementia were considered to be critical components of concerns or perceptions of people with dementia (Corner & Bond, 2004). However, these experiences are validated through open and honest discussions that take place during the PAC appointment and the healthcare professionals seek to increase diagnosis rates through the means of fostering trust and eliminating myths and misconceptions, acknowledging that stigma is a significant barrier to timely diagnoses (Nguyen & Li, 2020). The healthcare professionals in this study also discussed that there is a balance of discussing the topic of dementia sensitively but also candidly as they felt that it was essential to the construction of positive, trusting relationships that led to improved engagement of people with dementia in their care and enhanced diagnosis outcomes.

The third theme found that patients are more than their diagnoses. Specifically, great importance was placed on fostering resilience through comprehensive support and cultivating an understanding of living well with dementia (Whelan et al., 2020). Healthcare professionals emphasise the role of PAC in fostering resilience through holistic support, which includes clear communication and addressing misconceptions and stigma surrounding dementia (Kaduszkiewicz et al., 2008). The healthcare professionals recognised the challenges they faced when people with dementia and their carers sought health information from the internet and emphasised how accurate and individualised information provision within the PAC appointment was critical to enable informed decision-making. Furthermore, not only does the PAC appointment provide the healthcare professionals with a method of understanding the needs of people with dementia and those who care for them, it also helps the healthcare professional conducting it to identify any individual needs that can be referred to appropriate support services.

Additionally, the PAC appointment aids in informing people with dementia and their families of the reality of the condition, emphasising that a diagnosis does not signify the end of life but rather access to proper support and interventions can enable people to live as well as possible. The healthcare professionals in this study noted that it was important to be honest when discussing the progression of dementia but to balance this with discussion that encourages them to continue to engage in meaningful activities. PAC enables people with dementia to maintain QoL and do the things that they enjoy by reducing stigma and removing misconceptions. Many people with dementia report a decline in QoL, which is often in relation to poor support, services, information and stigma (Mate et al., 2012; Stites et al., 2017). However, research also indicates that people with dementia may not necessarily perceive a decline in quality of life directly following diagnosis (Ready & Ott, 2003). This holistic approach to support and informed decision-making throughout the diagnostic journey emphasises the importance of empowering people with dementia to lead fulfilling lives beyond their diagnosis.

Practice implications

There appears to be a divide between commissioners and healthcare professionals as to what a timely diagnosis actually is versus what is meant by a timely diagnosis, something that Dhedhi et al. (2014) also allude to. Based on the present study's findings, healthcare professionals must be given the time to communicate information, support, and personalised care within the PAC appointment while ensuring that people with dementia and carers' needs are addressed. All parties within the triadic relationship benefit, but none more so than the person with dementia (La Fontaine et al., 2014). The results show that PAC is considered to be associated with better outcomes for people with dementia through tailored comprehensive care provision that seeks to address the needs of the dyad that are as unique as themselves, generating a more understanding and supportive environment.

This study implies what good PAC provision should include. It should consist of dedicated appointments placed early on in the dementia care pathway where people with dementia are provided with the time to consider information, discuss fears and anxieties, and be supported in managing their care. Such appointments need to safeguard the emotional and informational needs of people with dementia and their carers through the provision of holistic support, ensuring that the provision of care is not impersonal or pressured, which has the potential to result in reduced well-being and outcomes for both people with dementia and those who care for them.

Although the effects of PAC within dementia care appear to be clearly demonstrated, the appointments that the healthcare professionals in this study conduct are not universally available in all NHS Trusts. In order to ensure that all people with dementia are able to benefit from comprehensive care leading to timely diagnoses, consistent implementation of

PAC is required. The potential for these appointments to improve outcomes for people with dementia should be recognised. Specifically, Williams (2004) calls for organisations such as the Alzheimer's Society to conduct these appointments, suggesting that they are well placed to perform these and the findings from this study support this suggestion.

The Alzheimer's Society is a well-established national organisation within the UK that provides information, support and guidance to people living with dementia and those who care for them (Alzheimer's Society, 2022). They have the necessary infrastructure to offer PAC more broadly through a highly experienced workforce of dementia advisors and support groups and provide non-clinical support, bridging the gap between clinical care and community support (Alzheimer's Society, 2022). Should the Alzheimer's Society extend its services to include non-clinical elements of PAC provision, accessibility would not only be significantly improved but the burden on NHS services would also be reduced (Stewart et al., 2022), enabling a consistent framework for dementia care across the UK. Previous research suggests that people frequently feel more at ease discussing sensitive topics such as dementia, with groups and organisations that are dedicated solely to their condition as opposed to just clinical settings (Pinto et al., 2022), which could help encourage rapport and trusting relationships. Therefore, groups such as the Alzheimer's Society are not only logistically well-positioned but also regarding rapport and trust-building, known components for effective PAC.

Research implications

Although previous studies have discussed the benefits of PAC, its implementation remains limited in dementia care, as noted earlier in this chapter and in Chapter 2. Further research should explore the impact of PAC on families and carers of people with dementia by comparing those who receive specialised PAC with those who do not. It would be beneficial to determine the efficacy of PAC by directly comparing the perceived usefulness and satisfaction of the initial appointment of carers who have experienced a PAC appointment with those who have not. Further research should be undertaken to determine how PAC affects fear of dementia and well-being in people experiencing cognitive decline. Measuring this before and after PAC appointments would determine how PAC impacts self-marginalisation and stigma. The construction of a clinical framework for PAC rooted in empirical evidence may lead to a gold standard model of dementia care that can be implemented across NHS Trusts and organisations such as the Alzheimer's Society.

Regardless of the perceived benefits of PAC, further exploration of questions raised in this study are needed to determine the broader implications of PAC. Firstly, it is necessary to examine the cultural adaptability of PAC as literature suggests that interactions with healthcare services are profoundly shaped by cultural perceptions of dementia (Gove et al., 2021). PAC should be evaluated as to how culturally informed care within these appointments could improve not just diagnosis rates but the experiences of people with dementia and their carers from ethnic groups. Additionally, the impact of healthcare professionals' own backgrounds and cultural competence on PAC effectiveness should be clarified. Another key area for further study is PAC's effectiveness across different healthcare settings beyond the NHS context, as varying healthcare structures may influence PAC's reception and impact. Addressing these issues could strengthen PAC's universality and identify best practices for integrating it into a range of dementia care pathways. Future research should also consider the economic implications of scaling up PAC, including the cost of training, supervision, and staff time, as well as the potential for long-term cost savings through earlier diagnosis, reduced carer burden, and more efficient use of post-diagnostic services.

Strengths and limitations

This study utilised qualitative methodology to prioritise healthcare professionals' perspectives, discussing concepts that enhanced the depth of the data as opposed to quantitative research. The study recruited from a multidisciplinary team of psychologists, advanced care practitioners, nurses and occupational therapists specialising in caring for people with dementia, which facilitated a deeper contextualised understanding of the study's findings. The study has been able to understand the psychological implications of potentially receiving a diagnosis of dementia and how these are sensitively mitigated through the people who support individuals living with dementia and carers through this process.

The recruitment strategy would have attracted those with strong views about PAC and its implementation as these individuals might have been more forthcoming in participating. Another limitation of this study is the potential for self-selection bias. The healthcare professionals who chose to participate may have held more favourable views of PAC, been more engaged with the concept, or felt more confident in their implementation of PAC compared to those who declined. As a result, the findings may overrepresent positive experiences or particular professional perspectives.

As interviews were conducted via Microsoft Teams, the healthcare professionals could be in an environment of their choice. They could be available with significantly more convenience to themselves as they chose the day and time that they wished to be interviewed. No demographic data was collected from healthcare professionals as the recruitment was from within the same team of a singular NHS Trust, and this may have provided the potential for identification. Further studies are required to determine how the characteristics of both people with dementia and healthcare professionals affect the effectiveness of how PAC appointments are conducted.

This study has some limitations, including the influence of culture. Findings in previous literature have demonstrated the influence that cultural factors can have on interactions between healthcare professionals and patients (Brook et al., 2018; Gove et al., 2021) and participants in this study did not discuss how these potentially impact upon the effectiveness of PAC in enabling timely diagnoses. Furthermore, because this study was conducted within a single NHS Trust, the results here have limited generalisability to other healthcare settings. Therefore, the applicability of PAC in different cultural settings is unknown, as perceptions of dementia and availability of services can differ within the dementia care pathway. For example, cultural misconceptions and stigma can prevent people with dementia from seeking clinical support when they first notice symptoms of cognitive decline resulting in delayed diagnoses and benefits of care and intervention early on in the dementia care pathway (Gove et al., 2021). Furthermore, it is essential that healthcare professionals have the cultural awareness to ensure that PAC is accessible and effective for people with dementia and their carers from diverse backgrounds (Ben-Ayre et al., 2024). More formal support mechanisms such as reflective practice and clinical supervision are required to assist healthcare professionals in meeting the emotional elements of PAC to ensure that that information and care provision remain culturally appropriate. PAC may be under-recognised as a critical component of healthcare professionals’ care provision, as evidence by the lack of empirical evidence within the dementia care pathway, as noted in Chapter 2. As such, formal support measures coupled with additional training, could support healthcare professionals in facilitating PAC appointments where they, as well as people with dementia and those who care for them can reap substantial benefits.

Conclusion

Based on the results of this study, it has been observed that PAC is crucial in the dementia diagnosis process for people with dementia and those who care for them, and provides recommendations for practice among healthcare professionals who provide PAC and to inform future research. Employing reflexive thematic analysis, three main themes were identified. First, it was noted that through PAC, people with dementia are put at the centre of their care. Second, significance was stressed on candid communication. Third, people with dementia realise that they are not defined by their diagnoses. These findings specifically relate to the delivery and impact of PAC in dementia care, and they demonstrate a need for the dementia care pathway to take a more comprehensive and holistic approach that focuses beyond the need for driving diagnosis rates, but to ensure that the autonomy and well-being of people with dementia are supported through personalised care that address a myriad of multifaceted needs. Additionally, this study recommends directions for further research to investigate the impact of PAC on carers and to develop a clinical framework to standardise practice founded on empirical evidence. It discusses the significance of patient-centred care, where collaboration between people with dementia, carers and healthcare professionals facilitates timely diagnoses that supports fulfilling and meaningful lives post-diagnosis. By acknowledging the importance of PAC within dementia care pathways enables better outcomes and QoL for people with dementia.

Chapter 5: Impact of Pre-Assessment Counselling on Psychological Well-Being in Dementia: Addressing Fear, Depression, Anxiety, and Stress

Chapter 4 found that healthcare professionals viewed PAC as being invaluable in facilitating patient-centred care that enabled timely diagnoses. Chapter 5 seeks to expand on this by exploring the impact of PAC upon the psychological well-being of the patients they deliver it to. The healthcare professionals in the previous chapter utilise the Depression, Anxiety and Stress Scale (DASS-21) within their clinical practice, and these psychological components are essential for reducing stigma and maintaining quality of life for people with dementia following diagnosis.

The previous chapter of this thesis found that healthcare professionals considered that PAC enables people with dementia to feel in control of their diagnosis journey and that candid conversations were essential to its success where people with dementia would understand that a diagnosis of dementia need not define them, meaning that the quality of their life (QoL) may be maintained. In order to confirm this, the present study builds upon those findings by directly measuring the well-being of people with dementia in relation to experiencing PAC by exploring fear of dementia, one of the largest barriers to dementia assessment and a significant impactor of a person's QoL. It also explores the impact PAC has upon depression, anxiety and stress which are frequently found to be comorbid with dementia. By exploring whether PAC effectively mitigates one of the largest barriers to dementia assessment, fear of dementia, this chapter directly builds on the groundwork established in Chapter 4. Although healthcare professionals consider PAC to be a valuable component of the dementia care pathway, previous research into PAC has notable limitations including inconsistency in delivery and small sample sizes (Carpenter et al., 2008). Despite showing promise in its effectiveness, the optimal implementation and the long-term benefits of PAC demonstrate the requirement for further research. For example, PAC may reduce feelings of fear and distress towards dementia and if so, if these are sustainable over time (La Fontaine et al., 2014). The present study seeks to address these questions and add to research surrounding PAC and its role in dementia care pathways.

The perceived challenges associated with a dementia diagnosis have made it the most feared condition among older adults, surpassing even cancer (Tang et al., 2017), as noted in Chapter 3. Chapter 4 demonstrates how healthcare professionals perceive the ability of PAC to improve emotional well-being and reduce fear of dementia, and Chapter 5 seeks to verify these views with empirical analysis of participants undergoing PAC. Dementia imparts a significant burden on people who live with the condition, those who care for them and upon society with financial, emotional and psychological consequences (Zhang et al., 2023), the latter of which include depression and anxiety, which are prevalent in people with dementia (WHO, 2022). Globally, 39% of people with dementia currently live with depression and/or anxiety, as compared with 5% of non-demented adults (Leung et al., 2021; WHO, 2022).

Dementia continues to be misunderstood and much stigma is attached to the condition (Corner & Bond, 2004). Media portrayals tend to highlight the most debilitating components of dementia, further perpetuating fear and negative stereotypes (Jolley & Benbow, 2000). Such representation increases the stigma of dementia and prevents health-seeking behaviours from people experiencing cognitive decline. Public awareness campaigns and the efforts of organisations such as the UK Alzheimer’s Society, Dementia UK, and the US Alzheimer’s Association have made strides in combating these misconceptions, but negative discourses remain pervasive (Siette et al, 2023).

Views on dementia are created throughout one’s lifetime through personal experiences and cultural contexts. Many people associate dementia with a loss of identity and dignity, particularly those who have previously cared for a person living with dementia (Corner & Bond, 2004; Read et al., 2017; Steeman et al., 2013; van Gennip et al., 2016). Therefore, it is understandable that some older adults may avoid seeking clinical advice if they should experience issues associated with cognitive decline, as if dementia is concluded, then this solidifies their perception of loss (Bradford et al., 2009). Fear of dementia is particularly understandable for people who have a family history of dementia as they may consider themselves to be at great risk of developing dementia in the future (Ostergren et al., 2017). People who have lived experience of caring for someone with dementia are also likely to be more anxious about developing dementia themselves as they may have witnessed particularly negative impacts of the condition, such as personality change or the loss of independence (Corner & Bond, 2004). However, it is not just people experiencing symptoms of cognitive decline or older adults who fear dementia. Literature has noted the increasing numbers of younger adults expressing anxiety and concern about dementia (Kessler et al., 2012; Cuddy et al., 2005).

When combined with negative stereotypes and attitudes, fear of dementia stops individuals from seeking assessment and diagnosis, thus delaying access to interventions or potential treatments that could slow disease progression (Yun & Maxfield, 2020). Whilst many individuals seek reassurance and support from family members and healthcare professionals if they recognise symptoms of cognitive decline, this is not true of those with increased levels of fear (Yun & Maxfield, 2020). Furthermore, depression, anxiety and stress can be exacerbated by fear, which in turn impairs cognitive functioning further and negatively impacts well-being (Beaudreau & O'Hara, 2009; Kessler et al., 2012). As formerly mentioned, the prevalence of depression and anxiety in people with dementia is higher and this adds to heightened stress and avoidance behaviour (Leung et al., 2021; WHO, 2022). As fear of dementia is frequently correlated with levels of stress, it can impact upon a person's cognitive performance and their ability to regulate emotions, adding to feelings of depression and anxiety (Yun & Maxfield, 2020). Understanding the relationship between fear of dementia and depression, anxiety and stress is essential, as these psychological states can affect overall health outcomes, quality of life, and timely intervention (Corner & Bond, 2004; Schichel et al., 2023). The potential of PAC to reduce this fear, and thereby improve psychological outcomes, forms the primary focus of Chapter 5. Although PAC appears to show potential, little research has been conducted in this area and studies tend to be of observational accounts and theoretical discussions (Carpenter et al., 2008). This chapter aims to reduce this gap in the literature by assessing the impact of PAC upon the well-being of people with dementia and enable further research into its role within the dementia care pathway.

PAC may be an appropriate intervention to reduce fear of dementia and the stigma attached to it by supporting the psychological adjustment of people with dementia throughout the diagnosis journey, providing support to enable comprehension and manage the potential emotional impact of receiving a confirmed diagnosis (La Fontaine et al., 2014). By assisting people with dementia to make informed decisions about their care, PAC helps to mitigate the fear of dementia and the stigma that someone might feel from experiencing cognitive decline, as literature suggests that dementia-related anxiety might be reduced when clear information and reassurance is provided (Carpenter et al., 2008). However, there is limited empirical evidence to establish if PAC reduces fear of dementia and its impact on mental health.

A critical question remains unanswered within PAC research, and that is to determine if PAC can tangibly reduce mental health symptoms among people with dementia, thereby providing a measurable psychological benefit beyond knowledge and preparedness. This chapter seeks to investigate this further.

Aims and Hypotheses

Where previous research has demonstrated that dementia is comorbid with several mental health disorders (Lueng et al., 2021; Regan & Varanelli, 2013), this study will investigate the impact of PAC on fear, depression, anxiety and stress in people with suspected dementia. PAC may be a valuable intervention in reducing fear of dementia and informational support throughout the diagnosis process (La Fontaine et al., 2014). Literature to support the potential effectiveness in reducing fear of dementia using PAC is limited, and former studies propose that people who fear dementia often display health avoidance behaviours, actively choosing not to engage with services potentially owed to negative connotations and stigma, which increases psychological distress (Cuddy et al., 2005).

This study seeks to examine the correlation between psychological distress and fear of dementia in people experiencing cognitive decline prior to receiving a confirmed diagnosis. By understanding the relationship between depression, anxiety, stress and fear of dementia, the present study hopes to develop a more comprehensive understanding of how a person's psychological well-being and health-seeking behaviours are impacted by fear of dementia (Suhr & Kinkela, 2007). This study hypothesises that 1) individuals who undergo PAC will experience a reduction in fear of dementia, and 2) that PAC will improve psychological well-being by reducing feelings of anxiety, stress, and depression.

Method

Design

This study was conducted in conjunction with the Early Intervention Dementia Service (EIDS) team, which operates within the Worcestershire and Herefordshire Health and Care NHS Trust. Ethical approval was sought from the Health Research Authority and following a panel interview, a favourable opinion was obtained (REC ref. 23/WM/0221). The study employed a repeated measures design to assess the immediate impact of PAC on the psychological wellbeing of people with suspected dementia. The participants completed two validated questionnaires one measuring fear of dementia and the other measuring depression, anxiety and stress (DASS-21) before and after their PAC appointments to directly compare the impact upon these psychological outcomes within the same individuals.

This study did not employ a control group as this would have been constructed of participants who were not receiving PAC, and whilst this could be argued as a limitation that could have provided comparative insights, the study was purposefully designed this way to reduce potential variability and directly attribute observed changes to PAC. Furthermore, the design of this study was deemed more ethical as it explores the impact of PAC without preventing a participant from accessing a potentially beneficial service. This study adopted a quantitative within-subjects design to compare participants' pre- and post-PAC scores across multiple outcome measures. This design reduces variability associated with individual differences and increases statistical power.

Participants

Participants comprised individuals with suspected cognitive impairments indicative of dementia, referred by their general practitioner (GP) to the EIDS team for further assessment. Potential participants were approached by the assistant psychologist within the team during their visit to the memory assessment service to discuss their potential involvement in the study. Exclusion criteria included individuals with diagnosed conditions known to affect memory, such as Myalgic Encephalomyelitis (ME) or fibromyalgia, as well as those with a history of epilepsy, stroke, or substance abuse. The study intended to recruit 34 participants so as to obtain a medium effect size (Brysbaert, 2019). However, a total of 17 participants were recruited. Recruitment for this study ended early due to a complaint from a participant and to mitigate any further negative impact upon wellbeing as a result of the research. Table 10 shows the demographic information collected from participants.

Table 10

Demographic information of participants

Demographic Variable	Category	*N*	%
Gender	Male	10	58.82%
	Female	7	41.18%
Age (years)	Overall mean (SD)	77.18 (7.17)	
	Males mean (SD)	78.60 (7.53)	
	Female mean (SD)	75.14 (6.96)	
Attending With	Spouse/partner	12	70.6%
	Child/grandchild/other family	3	17.6%
	Other	2	11.8%
Formal Years of Education	Range	10-17	
Marital Status	Married/civil partnership	14	82.4%
	Widowed	3	17.6%

Although demographic information was collected (see Table 10), due to the relatively small sample size in this study, it was not possible to include these variables as covariates without compromising statistical power. While Chapter 3 identified some group differences by gender and relationship status, this study was exploratory and not powered to test interaction effects. Future work with a larger sample could examine whether the psychological impact of PAC varies across different demographic groups. Assumptions for parametric testing were assessed through visual inspection of histograms and review of skewness values. The distributions were approximately normal and paired-sample t-tests were therefore deemed appropriate for analysing pre- and post-PAC differences.

Data collection was discontinued after a participant raised a complaint regarding the content of the questionnaires. In response, the EIDS team halted recruitment, and the sample was finalised at that point. At the time, the project was already approaching the end of the PhD data collection period, and there was insufficient time remaining to amend the study materials, secure additional ethical approvals, and resume recruitment.

Materials

The study utilised printed questionnaires comprising: a participant demographic questionnaire, capturing participant gender, age, who they attended the appointment with, the number of years formally spent in education and their marital status. These specific demographics were chosen due to their relevance in shaping psychological responses to dementia diagnosis and related anxieties. Age is an important consideration as the correlation between age and developing dementia is well understood, and the views held by people towards dementia are known to vary according to life stage (Tang et al., 2017; Yun & Maxfield, 2020). As mentioned elsewhere in this thesis, gender is known to influence healthcare-seeking behaviours as well as emotional responses and caring roles (Phillipson et al., 2015). The education attained by an individual influences health literacy and their understanding of information (Leung et al., 2021) and marital status impacts the availability of social support, which can help reduce fear and distress in dementia (Corner & Bond, 2004). By exploring these particular variables, a comprehensive understanding of the factors that impact the participants' experience of PAC can be obtained. Participants first completed the Fear of Dementia (FOD) Scale, where they answered questions designed to evaluate fear of developing dementia. The scale consisted of 29 items and was rated using a 5-point Likert scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Example items include "*I worry that I will forget important things in the future*" and "*I am afraid that I will develop dementia as I grow older.*" The FOD scale was selected for its focus on general dementia-related fears rather than specific types of dementia, making it appropriate for individuals with cognitive impairment who are undergoing assessment and may not yet have a confirmed diagnosis.

Other scales to assess fear of dementia were considered for this study, but whilst they were valid measures, they frequently included items that specifically referenced Alzheimer's Disease. As such, these were discounted to ensure that the participant could not be led into assuming a specific diagnosis would be the outcome of an assessment. Furthermore, not only are there over 100 types of dementia (Li et al., 2017) that a person could be diagnosed with, but it is also possible that the participant might not receive a diagnosis of dementia at all following assessment. As such, the wider approach that the FOD scale took was considered to be more suitable to reduce any assumptive bias (Minkyung & Dukyoo, 2020). The FOD scale has demonstrated good internal consistency with Cronbach's alpha being reported at .91 in Minkyung and Dukyoo's (2020) study, indicating high reliability. As the study was conducted within a busy clinical setting, the self-reporting format made it more feasible and accessible for participants to provide their responses independently. This design is also beneficial to the context of the study as it seeks to explore the subjective feelings which aid in evaluating psychological factors of fear and anxiety, aligning with the aim of examining the personal perceptions of well-being in people with suspected dementia owing to PAC.

The Depression, Anxiety, Stress Scale (DASS-21; Gomez, 2016) is a 21-item self-report questionnaire designed to measure the emotional states of depression, anxiety, and stress. The scale was constructed of three subscales consisting of 7 items for each of depression, anxiety and stress and items were rated on a 4-point Likert scale ranging from 0 (*did not apply to me at all*) to 3 (*applied to me very much, or most of the time*). Example items include "*I felt down-hearted and blue*" for depression, "*I felt close to panic*" for anxiety, and "*I found it hard to wind down*" for stress. The DASS-21 has been widely used in both clinical and non-clinical populations and has shown strong psychometric properties. Gomez (2014) reported Cronbach's alphas of 0.94, 0.87, and 0.91 for the depression, anxiety, and stress subscales, respectively, demonstrating excellent internal consistency. The DASS-21 was chosen for this study due to its ease of administration and reliability. It is also routinely used by healthcare professionals during PAC appointments, so it was not a new measure to learn or implement.

Procedure

Participants were selected from new referrals made to the EIDS team from the GP for further cognitive assessment. The assistant psychologist screened the potential participants for eligibility and telephoned them to ask if they would like to receive information on the study. They were informed that the study aimed to evaluate the effectiveness of their PAC appointment and were assured that there were no right or wrong answers. For those who agreed, a participant information sheet was sent alongside a letter confirming their PAC appointment. When participants arrived for their PAC appointment, they were asked again by the assistant psychologist if they would still like to take part and those who confirmed then provided informed consent and were assured of their right to withdraw from the study at any point, with their data subsequently destroyed. Each participant created their own unique identifying code to ensure anonymity and was informed about their right to withdraw consent for using their data following the study. The questionnaires were presented to the participants upon their arrival at the clinic prior to their PAC appointment by the assistant psychologist, who remained present during the completion of the questionnaires to answer any questions that the participants may have had about the items. Once the participants had self-reported their responses, the assistant psychologist sealed the completed questionnaires and consent forms in blank envelopes. Three days after PAC, the assistant psychologist administered the questionnaires again, where participants evaluated PAC's impact when considering each item. The decision on when to administer the post-PAC questionnaires was influenced by the clinical psychologist who led the EIDS team. Initially, the research team had planned to administer the post-PAC questionnaire immediately following their appointment but took the advice and expertise of the PAC delivery team who recommended that participants be given more time to process the informational and emotional content of the appointment first. This would generate more reliable data and reflect enduring psychological impacts as opposed to immediate reactions (Wener et al., 2012). These completed post-PAC questionnaires were completed 3 days later where the assistant psychologist would visit the participant in their home, and then placed in the same sealed envelope as the pre-PAC questionnaires for data collection. Following completion of the study, participants were debriefed through a debrief sheet, which provided further information about the study and contact details for the research team. The sheet also included signposting to appropriate support, advice, and information services that participants could access if they felt it necessary.

Results

Descriptive statistics were first calculated to summarise the key characteristics of the data. This included the means, standard deviations, and skew of the primary variables, depression, anxiety, stress, and FoD, both before and after participants received PAC. The descriptive output demonstrates how the data is distributed and enables an understanding of the characteristics before the inferential analyses occur. Each paired samples *t*-test had the normality assumption and skewness assessed, and each variable was within the parameters for parametric testing (see Table 11).

Table 11

Variable means, skew and kurtosis

	Depression Before	Depression After	Anxiety Before	Anxiety After	Stress Before	Stress After	FoD before	FoD after
Valid	17	17	17	17	17	17	17	17
Mean	10.71	9.29	8.94	9.29	13.53	10.59	68.65	62.06
Std. Dev.	11.53	8.54	9.57	11.2	10.94	10.9	24.56	23.55
Skew	1.58	0.54	0.98	1.57	0.65	0.8	0.52	0.64

Table 12 shows the results from the repeated-measures *t*-test that was used to compare FoD, depression, anxiety and stress scores before and after PAC. The analysis, as illustrated in Table 12, reveals that stress scores were significantly lowered after PAC (M = 10.59, SD = 10.9), compared to before (M= 13.53, SD = 10.94), *p* = .05, with a medium effect size, *r* = 0.25.

Table 12

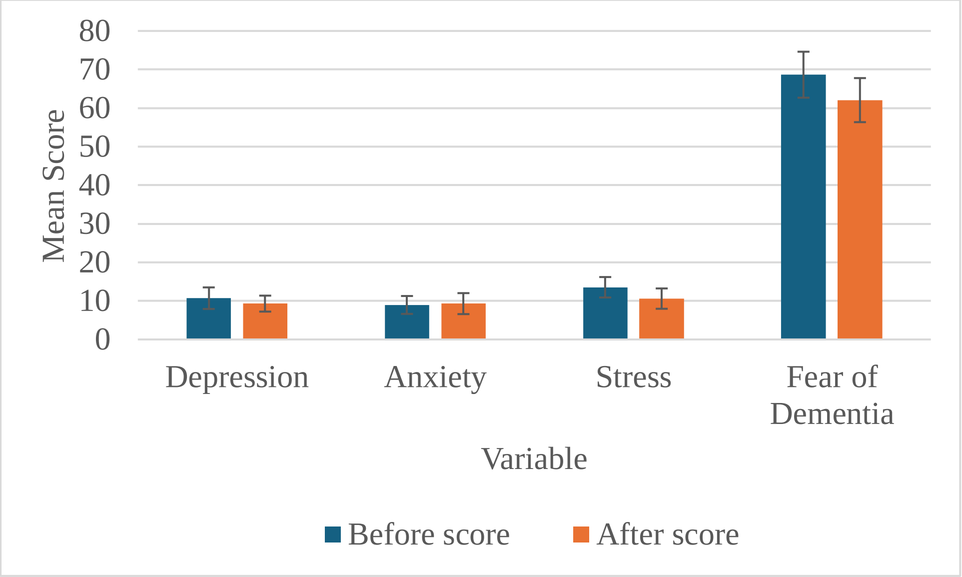
Paired Samples T-Test for DASS-21 Scores

Measure 1		Measure 2	*t*	*df*	*p*	Cohen's d	SE Cohen's d
DepressionBefore	-	DepressionAfter	0.81	16	0.43	0.20	0.16
AnxietyBefore	-	AnxietyAfter	-0.18	16	0.86	-0.04	0.18
StressBefore	-	StressAfter	2.13	16	0.05	0.52	0.13
FoDbefore	-	FoDafter	1.57	16	0.14	0.38	0.18

Figure 2 illustrates the significant difference in stress scores between the pre- and post-PAC conditions, further supporting the findings shown in Table 12.

Figure 2

Pre- and post-PAC mean scores for each condition



Discussion

This study aimed to assess the impact of PAC on fear, depression, anxiety, and stress in people with suspected dementia, hypothesising that PAC would improve psychological well-being by reducing these outcomes. The results showed a significant reduction in stress following the PAC appointment (Table 12), but no significant changes in fear of dementia, depression, or anxiety. Thus, while the hypothesis was partly supported, the findings highlight that PAC primarily alleviates stress rather than broader psychological distress. This stress reduction may reflect PAC's role in clarifying the diagnostic process and offering emotional support. Overall, the findings highlight the value of integrating PAC into clinical practice to enhance psychological well-being during dementia assessment.

Although this study found supportive evidence for one of the psychological factors of the journey to diagnosis, it is important to recognise that it still adds to the existing literature by offering one of the first quantitative evaluations of PAC on the psychological outcomes of people experiencing cognitive decline. Furthermore, by demonstrating the potential limitations of PAC's effect on fear, depression, and anxiety, the study highlights the need for more comprehensive or ongoing support systems in dementia care. These insights are valuable for both clinical practice and future research, suggesting that while PAC can reduce stress, it may need to be paired with additional interventions to address a broader range of psychological needs.

The Stress and Coping Theory (SCT; Lazarus & Folkman, 1984) supports the finding that PAC provision leads to decreased stress levels in people with suspected dementia. That is because SCT suggests that people are able to better cope with stressful situations and environments when they feel in control over their circumstances (Lazarus & Folkman, 1984). PAC provides an opportunity for individuals to manage the uncertainties associated with dementia assessment by clarifying the assessment process, discussing potential outcomes, and providing emotional support. SCT emphasises problem-focused coping techniques, which include determining and comprehending the cause of the stress. PAC aims to empower people with dementia to take control of their dementia diagnosis journey, thereby potentially reducing any associated stress.

Although the findings of this study note that stress scores significantly decreased following PAC, the same could not be said of those measuring fear of dementia, depression and anxiety. Therefore, it can be argued that PAC only helps in managing immediate stress responses and thus creates a platform for changes in other psychological measures in the long run. However, this study also revealed that there were no significant differences in fear of dementia, depression and anxiety. Therefore, despite notable changes in stress scores, any changes in fear of dementia, depression and anxiety may not be as evident and may be owed to a number of reasons. While PAC appears to be successful at reducing immediate stress felt by people with dementia, questions remain over why its impact upon fear, depression and anxiety is varied. One possible explanation for the limited change in anxiety and depression scores is that participants may not have been fully aware of, or willing to acknowledge, these emotional states at the time of PAC. Stoicism, denial or a focus on practical concerns over emotional ones may have contributed to underreporting. This aligns with findings from previous studies which suggest that people in the early stages of dementia often minimise emotional distress or prioritise cognitive concerns over psychological ones (Clare, 2002; Karnieli-Miller et al., 2012). It is also possible that the emotional impact of receiving a diagnosis had not yet fully emerged at the time of PAC and may become more pronounced in the weeks or months that follow. Further research should determine if the focus of PAC upon immediate stressful factors is adequate or if alternative approaches to intervention and support are required for persistent stress. It may be that specific topic conversations are needed within the PAC appointment, such as discussing fear of dementia or ensuring that enough time is given to this particular subject if a person with dementia needs more reassurance. Additionally, it is important to understand if the person with dementia has encountered dementia before in their personal or professional lives or if they believe themselves to be at risk of developing it. This would impact how they experience PAC, and healthcare professionals can then adapt their approach to ensure that they seek to address these psychological components, which will result in optimal benefits for the person with dementia. Clarifying these aspects would allow for a more nuanced understanding of how PAC could be adjusted to meet diverse patient needs.The variability in how the healthcare professionals delivered PAC was a major limitation of this study. A complaint from a participant highlighted significant differences in PAC provision which was previously unknown to both the research team and to the neuropsychologist who led the EIDS team. It was discovered that some of the healthcare professionals who had been conducting the PAC appointments took the time to ensure that all aspects of PAC were covered, whilst others conducted appointments hurriedly and then moved on to the assessment aspect, which may have also affected the participants' experiences and the overall success of PAC. The absence of a standardised framework for PAC meant that participants' experiences varied widely, potentially affecting their psychological responses and the study's outcomes. Standardising PAC delivery could address these inconsistencies and improve its overall effectiveness.

A study by Corner and Bond (2004) found that the knowledge, expectations, fears and anxieties towards dementia held by older adults are incredibly diverse, suggesting that whilst a standardised framework would be valuable in ensuring consistency and high-quality delivery of PAC, there must be room to be flexible to meet the individual needs of people with dementia. A gold standard approach would balance structured elements of PAC delivery with the adaptability required to address each individual's unique concerns, enhancing the effectiveness of PAC while maintaining consistency across services. This variation highlights the need for tailored approaches, as a standardised method for PAC may not adequately address the diverse needs of individuals. The limitations of PAC in alleviating fear of dementia, depression and anxiety could potentially be explained using Self-Determination Theory (SDT; Deci & Ryan, 2012). Consistent with SDT, when individuals feel competent, in control and are supported to make meaningful contributions in directing their healthcare journey, their well-being improves (Deci & Ryan, 2012). Thus, in relation to PAC, the optimal benefit for people with dementia comes with the sense of being actively involved within the PAC appointment where they are supported in understanding and managing their dementia diagnosis journey and their autonomy is respected. As this study found, following its cessation of data collection, the inconsistency of structure to the PAC appointment from the healthcare professionals almost certainly attributed to this, where some people with dementia received a full PAC appointment, and others received minimal PAC before continuing. The explanation provided for this was the need to work through the backlog of patients referred during the COVID-19 pandemic, and the healthcare professionals were working overtime and at weekends to reduce the numbers. However, should PAC be conducted thoroughly and customised to meet the needs of people with dementia fully, they subsequently feel empowered within the appointment which in turn should reduce the feeling of fear, depression and anxiety. By including SDT into PAC, its approach supports people with dementia to ask questions, raise concerns and engage in honest conversations on dementia which can result in improved well-being.

This study had a small number of participants which will have had implications upon statistical power. The study had intended to recruit 34 participants for a medium effect size

(Brysbaert, 2019), and therefore statistical power was reduced by cessation of recruitment after obtaining 17 participants, regardless of having found significant stress score reduction. Additional limitations include the use of self-reporting measures. This is because responses can be influenced by transient emotions, resulting in measurement variability (Kerr & Kerr, 2001). This study administered the post-PAC questionnaires 3 days following PAC in an attempt to minimise this, but as dementia is a highly emotive subject, it is possible that biases may still have been present.

This study did not include a control group, which limits the ability to draw causal inferences about the impact of PAC on psychological wellbeing. While alternative designs involving comparator groups were considered, these were ultimately not feasible within the scope and timescale of the doctoral research. Recruiting an additional sample of participants who had not received PAC would have required ethical approvals across multiple NHS Trusts and significantly extended the data collection period beyond what was possible within the funded duration of the PhD. Future research should seek to incorporate a comparison group, such as individuals on a waiting list or those receiving information-only support, to enable more robust evaluation of the intervention's effectiveness.

The lack of significant changes in fear of dementia, depression, and anxiety may partially result from these individual differences. Participants who had higher scores of these in the pre-PAC stage might not have obtained the same benefits of PAC than those who had lower scores, suggesting that the PAC they received might not have been as thorough or as personalised which may have addressed their psychological needs.

Implications

By evaluating participants' knowledge and expectations, PAC can be more effectively tailored to meet individual needs resulting in better emotional and psychological outcomes. The findings from Corner and Bond (2004) suggest that by understanding the varied needs of older adults, both voluntary and statutory organisations can design a PAC framework that leads to better and more efficient support for people with dementia. For example, constructing support programmes that incorporate education on particular fears or misconceptions of dementia could aid PAC appointments by providing supplementary support to people who proceed to an assessment (Skov et al., 2022). For example, creating educational materials and support programs that address specific fears and misconceptions about dementia could complement PAC and provide additional support to individuals undergoing cognitive assessments (Skov et al., 2022).

Study Limitations

A number of limitations and challenges faced within this study have already been alluded to. A primary concern was the necessity to discontinue the study after enrolling 17 participants due to a complaint regarding the implementation of both PAC and the research itself. This demonstrates that the wording used in particular items on the questionnaire and the provision of PAC may have negatively impacted upon the participants' well-being. Therefore it is possible that this study could have had unintentional consequences such as increased distress through its design when coupled with the lack of PAC provision from some healthcare professionals. Future research should ensure that questionnaire items put to participants are balanced to reduce any potential distress.

The findings of this study may have been impacted by participation selection bias. For example, whether an individual chose to take part in the study may have been determined by their level of anxiety of receiving a diagnosis (Tripepi et al., 2010). It is possible that the mean anxiety scores were higher in the post-PAC condition as the result of individuals who were already anxious about the dementia diagnosis journey and for whom participating in this study was an additional stressor.

Another limitation was the use of the FOD scale, which, despite being validated, primarily focuses on the negative aspects of dementia. The FOD scale's emphasis on negative aspects may have limited its ability to capture the full range of participants' experiences and fears. A more balanced measure that includes both positive and neutral aspects of dementia could have provided a more comprehensive understanding of participants' attitudes and the impact of PAC (Park et al., 2024). Fear may have been increased, or nuanced improvements from the PAC appointment may have been overshadowed by the high number of negatively worded items in the FOD scale.

This study employed a repeated measures design to examine changes in psychological wellbeing following PAC for individuals with suspected dementia. However, the absence of a comparator group limits the ability to attribute observed improvements solely to the intervention. Future research could incorporate a waiting list comparison group, drawing on individuals who have been referred to the service but have not yet received PAC. Assessing outcomes such as fear of dementia, depression, anxiety, and stress prior to the intervention would allow for more robust inferences regarding PAC's effectiveness. An alternative approach may involve the inclusion of an information-only group, in which participants receive standard written materials without a structured conversation. The use of such pragmatic comparator groups would not only strengthen causal interpretation but also support the generation of cost-effectiveness evidence, which is critical for informing implementation and commissioning decisions in the context of resource-limited services.

Study Reflection

In the course of this study, a complaint lodged by a participant raised essential considerations regarding the emotional impact of the scale language and item content on people with dementia. Specifically, the participant expressed concerns about the perceived negativity of the scales. Although the use of questionnaires and scales is extremely useful for quantitative analysis, they can impact immediate emotional responses, and where these are used in particularly vulnerable populations such as people with dementia, the concern increases. For instance, Yun and Maxfield (2020) discuss how fear of dementia often intensifies emotional responses to assessment content, suggesting that scale language may need to be carefully adapted to avoid exacerbating these fears. This feedback from the participant highlights the importance of developing assessment tools that respect the dignity and experience of people with dementia, especially during diagnostic and evaluative stages. When the focus of items is on negative constructs, there is the capacity to reinforce feelings of fear and distress (Beaudrea & O'Hara, 2009; Leung et al., 2021). Therefore, when using such scales, it is important to be mindful that there is a higher prevalence of comorbidity with psychological conditions in this population, such as depression and anxiety (WHO, 2022), as they can impact upon how people with dementia view their experiences and have repercussions for their future engagement with continued care (Lueng et al., 2021). As highlighted by the participant's feedback, the emotional toll associated with the language in these scales suggests a need for research measures that balance diagnostic accuracy with a sensitivity to the individual's emotional and psychological experience.

Future research implications

Although this study mainly identified decreases in stress after PAC, the potential relationships between fear of dementia and wider psychological issues, including depression, anxiety, and stress, suggest areas for further investigation. Existing research indicates that fear of dementia can affect both the tendency to seek help and an individual's overall psychological health (Suhr & Kinkela, 2007). Whilst this study did not find these particular associations from its results, it is possible that PAC appointments could be a supportive intervention that reduces psychological barriers to healthcare-seeking within the dementia care pathway. Future studies should attempt to examine these correlations and the effect of healthcare seeking behaviours and psychological outcomes if fear of dementia is reduced.

Additionally, future research may also want to replicate this study and then amend the FOD scale, where some of the items that are currently negatively phrased could be rephrased in a more neutral manner. Such measures might recognise both the difficulties and potential coping strategies, which could enhance participant comfort and improve the reliability of data. Moreover, investigating specific language that people with dementia and their carers find reassuring or positive could inform the creation of scales that more accurately reflect the lived experiences of dementia without perpetuating stigma (Siette et al., 2023).

Developing a standardised PAC framework is critical for successful implementation as it would guarantee a uniform approach to the delivery of the PAC appointment from all healthcare professionals. Therefore, this standardised approach to PAC would eliminate the variability in its delivery, leave less room for interpretation and ambiguity, and ensure that all people with dementia would receive consistent care and support. Previous research has found that if patient care is delivered using standardised protocols, it leads to enhanced patient results as it increases the quality and measurability of the care that is provided (Grol and Grimshaw 2003, Grimshaw et al. 2005).

Increasing the number of participants and making the sample more diverse can also help reduce biases that may arise from the current limited participant pool. A larger number of participants would help to determine if the outcomes observed are consistent across fear of dementia, depression and anxiety, as the increased diversity would mean that the results would be more generalisable, leading to a more effective approach to PAC that works for wider populations and demographics (Gobo, 2004). Furthermore, by using a questionnaire where the positive and negative components of dementia are more balanced could provide a more comprehensive understanding of the participant's experiences and the value of PAC, as the true impact of psychological interventions is more accurately reflected through items that describe the benefits and challenges (Schmidt et al., 2017).

Future investigations should also explore the varied perceptions and requirements of those at risk of dementia, including those who are currently healthy yet worried about cognitive decline. Research that focuses on individuals with differing levels of risk can uncover the psychological factors that shape fears and expectations regarding dementia, which could lead to more focused and effective interventions (Corner & Bond, 2004). Findings from Corner and Bond (2004) highlight the significant variation in knowledge, expectations, fears, and anxieties about dementia among older adults. This variability indicates that a universal approach to PAC may not be adequate. Nevertheless, a structured framework could incorporate flexible components to address the specific needs of individuals at various stages or risk levels. A standardised approach to PAC coupled with a certain degree of flexibility means that consistency can be maintained when seeking to address the individual needs and concerns of people with dementia. This means that PAC would be able to reduce fear of dementia across different populations, enabling an informative and supportive experience for people with dementia. Investigating the views of middle-aged individuals concerning fear of dementia would enable a broader understanding of how these concerns develop over time, and interventions to address these proactively could be developed. Previous research has demonstrated that concerns surrounding cognitive decline and memory frequently begin in middle-aged adults, meaning that through intervention, any long-term anxiety has the potential to be reduced if implemented early on (Cutler & Hodgson, 2001; Kessler et al., 2012).

It would be useful to understand the influence of PAC on the emotional states of people with dementia over time by conducting longitudinal studies and determining if PAC's benefits continue to impact beyond diagnosis. This would help in understanding the durability of PAC and how it aids in maintaining improvements in well-being over time (Kazdin, 2009).

Conclusion

In conclusion, this study has uncovered that PAC effectively reduces stress in people with suspected dementia before undergoing assessment. However, several limitations require addressing, including the low number of participants and, perhaps more importantly, the lack of consistency in PAC delivery by healthcare professionals. This is essential for ensuring PAC positively impacts and benefits people with dementia. In doing so and by utilising comprehensive questionnaires that have significantly more balanced items, further research can build upon the findings of this study to improve the current psychological support given to people with suspected dementia and provide them with the confidence to decide their next steps in the dementia diagnosis journey, improving the quality of care provision in this important area.

Chapter 6: Comparing the Benefits of Pre-Assessment Counselling with Standard Care: Enhancing Wellbeing for Dementia Carers

Chapter 5 investigated the impact of PAC on fear of dementia, depression, anxiety and stress in people experiencing cognitive decline. Results showed that PAC significantly reduced feelings of stress, but only a slight variation was measured in the other psychological outcomes. However, despite the study's limited success, the research demonstrated that psychological support at the earliest stages of the dementia diagnosis journey was critical. Individuals living with dementia are not the only people who are affected upon receiving a diagnosis but also those who care for them, and it is important to recognise that carers play a pivotal role in supporting people with dementia through their diagnostic and care journey. The present chapter shifts the focus to explore what kind of impact PAC can have on carers by comparing those who have received PAC to those for whom this service was unavailable, owing to their care needs being met by a different NHS Trust. It explores if PAC has the ability to enable psychological well-being and provide effective support. Building upon Chapter 5, which focused on the impact PAC had upon people with suspected dementia, Chapter 6 seeks to explore how PAC also benefits carers in optimising dementia care provision. Although one of the core components of PAC's design is to facilitate autonomy and improve well-being of people living with dementia, it also seeks to assist those who will step into the role of carer.

Much literature exists discussing the negative psychological impact of caring for someone with dementia, including stress, depression and burnout (Lee et al., 2013; Watson et al., 2019). Notably, earlier studies have established that carers who feel inadequately resourced and unsupported are more prone to psychological distress (Chang et al., 2020; Song & Kim, 2021). However, relatively few investigations have compared outcomes for carers receiving structured support like PAC with those who do not (Andrén & Elmståhl, 2005). As such, this gap in the research forms the basis for exploring how access to PAC can influence the well-being of carers in this study. Abley et al. (2013) note that carers frequently wish to receive more clarity and information throughout the dementia diagnosis journey and that challenges such as a lack of consistency in communication and information impact carer readiness and trust in clinical services. Because PAC aims to assist not just the person with dementia but also those who care for them, it is crucial to assess how it can be of benefit to carers to understand its effectiveness for this population.

Further to this, the carers included in this study possessed unimpaired memory and could, therefore, provide valuable insight into the experience of what the first appointment they had in a memory assessment service was like and how it impacted their well-being following diagnosis. Therefore, Chapter 6 deviates the focus away from the impact of PAC on the well-being of people with dementia to that of their carers. This study compares the experiences of carers who have received a PAC appointment with those who have not, aiming to determine how PAC can enhance the ability of carers to gain clarity of the dementia journey, manage challenges that may accompany a diagnosis and provide care and support to people with dementia. In doing so, Chapter 6 addresses a vital aspect of PAC's broader impact, providing insight into how it might enhance dementia care by supporting carers' psychological well-being. This final study reinforces the broader aim of this thesis in optimising dementia care through inclusive, person-centred strategies that consider the holistic needs of both people with dementia and their carers.

Carers of People with Dementia

Approximately 982,000 people live with dementia in the UK (Alzheimer's Research UK, 2023), and 670,000 people, usually family members, informally care for them (Carers UK, 2021). One in three people will take on this caring role for a relative or a friend within their lifetime (NHS England, 2022). In the UK, the government recognises carers as essential for dementia care as they provide essential support to their loved ones as well as relieving costs and strains on healthcare services (DoH, 2009). People presenting with cognitive impairment will often have an individual who would typically step into that caring role when visiting their general practitioner (GP) to discuss their observations of cognitive change and are then often referred to a memory assessment service for more comprehensive testing (Livingston et al., 2017). Memory assessment services are viewed as specialist diagnostic services (National Institute for Health and Care Excellence, (NICE), 2019) and have an integral role in ensuring people receive a timely diagnosis of dementia (DoH, 2015).

As GPs are often the first clinical practitioners to assess an individual's cognitive capacity (Phillipson et al., 2015), how the consultation is experienced by both the person with dementia and their carer is likely to play a key role in shaping an individual's understanding and confidence in future evaluations. This is because carers and patients have emphasised how much their first impression of healthcare professionals matters (Birt et al., 2020b), as does their ability to counsel and signpost (Foley et al., 2017). Furthermore, communication is improved when carers feel valued and listened to (Karlsson et al., 2015). This demonstrates the importance of PAC, which ensures that carers receive accurate information and feel acknowledged, establishes trust, and alleviates anxiety that may stem from the diagnosis process.

Caring for those with dementia poses distinct challenges for both people who are experiencing cognitive decline and their carers. While carers have reported both positive and negative experiences in their roles, negative experiences frequently arise when the carer feels unprepared to meet the demands placed upon them (Andrén & Elmståhl, 2005). Frequently cited sources of support include education about dementia (Corbett et al., 2012). As dementia is neurodegenerative and leads to functional decline, the responsibility of decision-making on behalf of a person with dementia is stressful for many carers (Samsi & Manthorpe, 2013). Evidence determines that involving carers closely in the care of people with dementia benefits the quality of care that they receive (Ablitt et al., 2009).

Effective communication and provision of information are essential components of quality care, particularly during the dementia diagnosis journey. Carers have emphasised the importance of having a comprehensive understanding of what to expect during dementia assessments and the possible outcomes of diagnoses, along with information about available resources (Abley et al., 2013). Nevertheless, Abley et al. (2013) indicate that many carers experience delays or gaps in information, which can heighten anxiety and complicate their ability to manage expectations throughout the diagnostic journey. When information is customised to meet the specific needs of the person under their care, it can significantly enhance carers' preparedness and diminish uncertainty (Abley et al., 2013).

Furthermore, obtaining a dementia diagnosis, regardless of its consequences, is commonly perceived by carers as an entry point to vital support services. Labelling cognitive changes not only aids in their comprehension of the dementia progression but also enables carers and their loved ones to gain access to potential treatments, resources, and routes for future planning (Morgan et al., 2014). By emphasising the importance of compassionate and transparent communication, healthcare providers can cultivate trust and foster supportive relationships with both carers and people with dementia, which has been demonstrated to enhance overall care quality (Smith et al., 2005).

Carers frequently desire more detailed, accessible information on prognosis, care planning, and legal considerations, such as power of attorney (Ng et al., 2021). Research suggests that involving family members in obtaining the person's background and in forward planning through structured meetings and accessible written resources can support carers in addressing immediate and future needs (Ryan et al., 2018). Meeting these needs is critical, as well-prepared carers contribute positively to the care trajectory and overall well-being of the person with dementia (Ng et al., 2021).

Understanding the Diagnostic Pathway and Pre-assessment Counselling

Samsi et al. (2013) explored the journey of a person living with dementia and their carer first entered a diagnostic service through to diagnosis disclosure, reporting on experiences, expectations and service needs. Their results stated that the service users found the referral process confusing, as the person with dementia was not always clear as to when the referral was supposed to take place, the purpose of the referral, and the possible outcomes not having been explained. Assessments conducted within secondary care were regarded as being even more confusing owing to people with dementia reporting that they felt overwhelmed by the appointments for tests and scans and participants stated that they did not understand as what determined a demonstration of 'good' memory. Anxiety is a commonly reported emotional response to the dementia diagnosis journey (Keady & Gilliard, 2002), especially owed to the waiting of an unknown outcome. Participants indicated that the absence of support during this period cultivated distrust regarding the service's intentions and heightened expectations concerning the results of the assessment process, as well as expectations for resolution following the disclosure of a diagnosis. These observations demonstrate the potential role of PAC in addressing deficiencies in clarity, support, and comprehension throughout the diagnostic pathway. PAC has the potential to reduce the anxiety and confusion reported through clear information provision as to what to expect from the diagnosis journey, such as typical assessments and possible outcomes. The structured approach of PAC means that the experience of the diagnosis journey for people with dementia and their carers is improved by managing expectations and reducing stigma, which fosters trusting relationships with healthcare professionals.

Unlike the standard initial assessment, which primarily focuses on cognitive testing and diagnosis (Shukla, 2003), PAC allows patients and carers to discuss concerns, ask questions, and receive clear and transparent information about the forthcoming diagnostic journey (La Fontaine et al., 2014). It offers an opportunity for patients to express apprehensions, such as the stigma associated with dementia or the fear of a diagnosis, while also enabling clinicians to begin establishing a supportive and trusting relationship with both the person with dementia and their carers. PAC is useful in facilitating the psychological adjustment that occurs during the diagnosis process, where the confirmation of dementia is a life-changing piece of news (La Fontaine et al., 2014). PAC explains the usefulness of dementia assessment and what to expect from the process. Assessment outcomes are also discussed, including a potential diagnosis of dementia, so PAC ensures people with suspected dementia are making informed decisions about assessment. Placing the person with dementia at the centre of this decision is essential given the significant social and psychological adjustment required upon receiving a diagnosis of dementia for both the person experiencing cognitive decline and their families (La Fontaine et al., 2014). PAC also provides opportunities to tackle stigma and explore possible fears that may be driven by underlying abilities, such as acknowledged cognitive changes: levels of fear are often correlated with the level of problems (Yun & Maxfield, 2020), highlighting the importance of exploration and discussion.

This study was conducted with the Early Intervention for Dementia Service (EIDS), a team that operates within a memory assessment service (MAS) in Worcestershire, UK, and has offered PAC since 2010. This is the first appointment that a person with dementia and their carer will meet with a clinician so they can be counselled and educated on the diagnosis process. PAC is under-researched, and so the present study aims to compare and contrast experiences and satisfaction with the initial appointment from a memory assessment service between populations of carers who have received an appointment solely dedicated to PAC with those who have not and obtained a more precise understanding as to the value of PAC for carers.

Research Focus, Aims and Hypothesis

This study utilised a mixed-methods approach, where quantitative data were gathered through questionnaires designed to capture the experiences and well-being of carers. These measures provide numerical insights into how PAC affects carers, facilitating a broad comparison between those who received PAC and those who did not. However, quantitative data cannot capture all the nuances and contextual factors that construct carers' experiences so this study sought to collect qualitative data using a free-text box situated at the end of the questionnaire. This was included so that participants could share any further thoughts that the items in the questionnaire did not address and provide any additional information that they felt was relevant to the study. This study was initially intended to be a quantitative design. However, the research team advised that it would be beneficial to include a qualitative component to ensure that as much information about the experience of the diagnosis journey was captured to provide a comprehensive understanding and interpretation of how PAC may benefit through this mixed-methods approach (Dawadi et al., 2021). This combination aids in clarifying the reasons behind observed quantitative outcomes and helps to pinpoint the underlying factors influencing carers' experiences. By combining quantitative and qualitative data, this research seeks to present a comprehensive perspective on the effects of PAC on carer experiences, ensuring that both measurable results and personal narratives of carers are taken into account when evaluating the effectiveness of PAC. As such, it is hypothesised that carers who have received a PAC appointment will indicate higher levels of well-being and more favourable experiences regarding the diagnosis journey than those who have not received such appointments.

Method

Design

The PAC appointment seeks to enable people with dementia to make decisions about their healthcare and they are encouraged to bring someone to support them to this appointment. This is a between-groups study of two carer groups where one group experienced PAC on their dementia diagnosis journey and the other did not. Ethical approval was sought from the Health Research Authority, and a favourable opinion was obtained after a panel interview (REC ref. 24/WM/0035). The primary quantitative data were collected using two questionnaires: the Initial Appointment Experience Scale and the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007). The secondary qualitative data were collected using a free-text box at the end of the questionnaire where participants could add anything that they wanted to share concerning their experience of the initial appointment.

The decision to use a mixed-methods approach was driven by the need to comprehensively capture carers' experiences, which are multifaceted and may not be fully conveyed through quantitative measures alone and provide depth and context to assist in explaining the observed outcomes of the qualitative data of satisfaction and well-being. The free-text option was chosen over other qualitative methods such as interviews, as they were logistically convenient where the completion of the study could be conducted at the participant's pace and enable reflection without the pressure of being observed or within an interview setting.

Participants

The study recruited 65 participants from each group as so to obtain a medium effect size (Brysbaert, 2019). Participants had either experienced PAC or had not experienced PAC before. Those who had experience of PAC were recruited from the Worcestershire and Herefordshire Health and Care NHS Trust, and those without experience of PAC were recruited from the Join Dementia Research (JDR) website. The JDR group served as a control, as they did not receive a formal, separate PAC appointment prior to the assessment appointment. JDR hold a register of people with dementia and carers who consent to be contacted to participate in research. Inclusion criteria were males and females who were the primary carer of a person with dementia. They must also have been present during the initial appointment with the person with dementia. There were no socioeconomic limitations and participants had to live in the East Midlands for the non-PAC condition and for the PAC condition, they must live in areas that are covered by the Worcestershire and Herefordshire NHS Health and Care Trust owing to the location of the Early Intervention Dementia Service (EIDS) to whom patients within this area are referred. Further, they could have no expression of memory impairments themselves and be fluent in English to understand information and the questions asked of them. Exclusion criteria included carers under 18 years old and those who had medical conditions that caused impaired memory.

This study was exclusive to carers to avoid ethical concerns surrounding asking people with memory impairments to recall details from past events accurately. This study sought carers who were at the initial appointment in the memory assessment service alongside the person with dementia to participate. Therefore, they would have experienced the diagnosis process and could provide reliable insights into the experience and impact of that appointment without the risk of memory-related biases. By focusing on carers' perspectives, the study aimed to capture a clear and comprehensive view of the PAC experience and its potential value in supporting patients and their families.

Table 13 shows the demographic characteristics of the carers in the PAC and non-PAC groups. The mean age of carers in the PAC group was 70 years (SD = 13 years) and 65 years (SD = 12 years) in the non-PAC group. There were 26 males (40%) and 39 females (60%) in the PAC group, and 23 males (35%) and 43 females (65%) in the non-PAC group. For both groups, most participants had further education, and the initial appointments were mainly experienced in 2023. The PAC group had a higher percentage of carers who were spouses/partners (74%) than the non-PAC group (57%), and Alzheimer's Disease was the most common response provided when asked about the diagnosis outcome in the PAC and non-PAC group (both 45%) respectively. Most demographic characteristics were relatively balanced across the PAC and non-PAC groups. However, these variables were not statistically controlled for as covariates, as the study was not powered to support multivariate analysis. The aim was to assess real-world group-level differences rather than control for individual background variables. Most demographic characteristics were relatively balanced across the PAC and non-PAC groups. However, these variables were not statistically controlled for as covariates, as the study was not powered to support multivariate analysis without compromising statistical validity. The aim was to assess real-world group-level differences rather than control for individual background variables.

Table 13

Demographic Characteristics of Dementia Carers by Group (PAC vs. Non-PAC)

Demographic Characteristic	Category	PAC Frequency	Non-PAC Frequency
Age	Mean (SD)	70 (13)	65 (12)
	Minimum - Maximum	42 - 87	38 - 88
Gender	Male	26 (40%)	23 (35%)
	Female	39 (60%)	42 (65%)

Demographic Characteristic	Category	PAC Frequency	Non-PAC Frequency
Education	Secondary school, no qualifications	4 (6%)	1 (2%)
	Secondary school, qualifications (O-level, CSE, GCSE)	19 (29%)	24 (37%)
	Further education	21 (32%)	21 (32%)
	Undergraduate degree (BSc/BA)	15 (23%)	16 (25%)
	Postgraduate degree (MSc/MA/PhD/Doctorate)	6 (9%)	3 (5%)
Year of Visit	2022	21 (32%)	29 (45%)
	2023	31 (48%)	30 (46%)
	2024	13 (20%)	6 (9%)
Relationship to Person with Dementia	Spouse/partner	48 (74%)	37 (57%)
	Child/grandchild/other family member	17 (26%)	28 (43%)
Diagnosis	Alzheimer’s Disease	29 (45%)	29 (45%)
	Frontotemporal Dementia	1 (2%)	0 (0%)
	Mild Cognitive Impairment	5 (8%)	3 (5%)
	Mixed Dementia	11 (17%)	19 (29%)
	Vascular Dementia	10 (15%)	12 (18%)
	Dementia, type not specified	9 (14%)	2 (3%)

Note: Percentages may not sum to 100 due to rounding.

Materials

The Initial Appointment Experience Scale was designed for this study to measure carers’ perceptions of the PAC appointment. It comprises 23 items structured on a 5-point Likert scale, with response options ranging from 1 (*‘definitely disagree’*) to 5 (*‘definitely agree’*). The development of the scale was an iterative process undertaken in consultation with two clinicians, one formerly from the EIDS team and the other currently working there. The initial items were derived from findings from a previous student’s research on carer experiences. Following the initial drafting of the scale, the items were reviewed by a research team member who used to work within the EIDS team. They provided suggestions to improve and refine the items which were subsequently amended as per their recommendations. The scale was then sent to the clinical neuropsychologist, who led the EIDS team to determine if it required any amends or additional items. Following this final consultation, the scale was deemed appropriate for use in the study. This collaborative process ensured that the scale was relevant and comprehensive in capturing carers' experiences with the PAC appointment. Example items include: "*The clinician provided clear information and advice about the assessment process for dementia*" and *"The PAC appointment helped me feel more prepared to support the person with dementia."* Though this scale is not a validated measure, it was designed to explore carers' subjective experiences in a structured manner, allowing for a systematic assessment of their perceptions of the PAC appointment. The scale demonstrated high internal consistency in this sample, with a Cronbach's alpha of .94, indicating high reliability.

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007) was used to evaluate carer well-being. This scale is constructed of 14 items that measure mental well-being, including positive affect, satisfying interpersonal relationships, and overall functioning. Participants rate each item on a 5-point scale, ranging from 1 ('*none of the time*') to 5 ('all of the time'). Example items include: "*I've been feeling optimistic about the future*" and "*I've been dealing with problems well*". The total score is calculated by summing the scores for each of the 14 items, with a range of 14 to 70, where higher scores equate to higher levels of well-being. The WEMWBS is a validated scale widely used within clinical and general populations. It has high internal consistency with a Cronbach's alpha of 0.90 (Tennant et al., 2007), making it a robust tool to measure PAC's impact upon carers' wellbeing.

As previously referred to, a free-text box was included at the end of the quantitative questionnaire to invite participants to provide further comments should they wish to do so. The prompt read, "Please feel free to add any comments that you may wish to share with us regarding your experiences with the memory assessment process below." By providing an opportunity for the participants to further discuss their experience of the initial assessment or their well-being in their own words supported the responses they provided from the questionnaires.

Procedure

This study employed Qualtrics to generate an online questionnaire to which a link could be sent to consenting participants. All participants recruited from JDR accessed the questionnaire through the link sent to them by email. For participants recruited from the Worcestershire and Herefordshire Health and Care NHS Trust, service users who had provided an email address as part of their contact details were emailed. Those who had not provided an email address received a letter through the post detailing the study and inviting them to participate with a shortened and simplified link within the letter body that they could copy into their browser to complete the study. Both groups were presented with the same questions to ensure measurement consistency.

The research team contacted carers from the East Midlands as the memory assessment services in this area do not provide a separate consultation to implement PAC prior to the one in which the assessment takes place. Participants were emailed via the JDR website with an explanation of the research and a link to take them to the study should they wish to participate. Participants who received a PAC appointment as part of their usual care in Worcestershire were contacted by the assistant psychologist within the EIDS team, which conducts PAC. The assistant psychologist screened the records of carers and sent them a letter including the details of the study and a weblink to participate, which was emailed to those from the control group.

Individuals who chose to enter the weblink and participate in the study were met with a copy of the Participant Information Sheet on Qualtrics. It reminded them of the purpose of the study and their right to withdraw, instructed them on how to create a unique identifying number, and asked for consent to proceed to answer the questionnaires and provide further elaboration on their experience and well-being using the free-text box. Participants were then debriefed and thanked for their time. Timescales were provided within which they could request data to be withdrawn, as well as signpost to information and support groups relevant to people who care for individuals living with dementia.

Data Analysis

This study was initially designed using quantitative methods, but following discussions with the research team, it was decided to incorporate a qualitative element as this could be included with relative ease owing to the format in which data was collected. Other forms of qualitative methods, such as focus groups, were rejected. This was because, whilst they could provide rich data, the logistical arrangement of organising convenient times that carers could attend, coupled with potential group biases, would be challenging. It was not considered appropriate for this study to have a solely qualitative approach as it was interested in measuring differences between groups. As such, the mixed-methods approach was employed to generate statistically generalisable data enhanced by detailed carer insights.

Quantitative Analysis.

Independent samples t-tests were used to compare outcomes between carers who received a PAC appointment and those who did not. This approach was appropriate given the two-group, between-subjects design of the study. Assumptions of normality and homogeneity of variance were assessed using descriptive statistics, graphical methods, and Levene’s test. These assumptions were sufficiently met to proceed with t-tests; otherwise, non-parametric Mann-Whitney U tests would have been considered. Although ANCOVA could have been used to adjust for demographic covariates, the study was not powered to support multivariate analysis. The primary aim was to explore group-level differences to understand the potential impact of PAC compared to standard care.

Prior to *t*-testing, the quantitative data were analysed using JASP software, where descriptive statistics, including the mean and standard deviations, were reported for the average score of each item of the questionnaires. This approach enabled key variables to be compared and provided insight into significant differences in experiences and well-being between groups.

Qualitative Analysis.

By including carers’ voices, the analysis moved beyond mere numerical trends to capture the subjective experiences of those who engage with PAC, providing a fuller picture of its impact on their well-being and satisfaction with the diagnostic process. The qualitative responses were analysed using thematic analysis. The process involved reading through all the responses to become familiar with the content, followed by coding key ideas and concepts that emerged from the data. Codes were then grouped into broader themes that captured the essence of carers' experiences. Themes were identified, highlighting both positive and negative aspects of the carers' experiences with the initial appointment and subsequent wellbeing. Qualitative data helps to understand the emotional and personal reflections of experiences, and these can be combined with quantitative observations to provide context (Creswell & Plano Clark, 2018). Mixed-methods research can enhance studies by combining the breadth of quantitative data and the depth of qualitative data, resulting in a more comprehensive and holistic understanding of the phenomenon being explored (Bryman, 2006). This study used thematic analysis to evaluate the qualitative data as it enables prominent themes from the carers' responses to be identified using a systematic approach (Braun & Clarke, 2006). Thematic analysis was appropriate for capturing subjective reflections and emotional nuances across individual experiences. Assumptions for thematic analysis included an expectation of rich, varied data that would yield meaningful themes, allowing carers' feedback to highlight both supportive and challenging aspects of PAC. In cases where responses were brief or lacked depth, themes were corroborated through repeated patterns across responses to ensure reliability in the qualitative findings.

Integration of Quantitative and Qualitative Data.

This study adopted a mixed-methods approach that incorporated quantitative data from independent samples *t*-tests used to identify significant differences in experience and well-being scores between the two groups. Thematic analysis was used to analyse the qualitative data to contextualise and enhance the quantitative findings and capture any persistent themes (Braun & Clarke, 2006). When combined, these methods capture both the objective and subjective truths of carers experiences, enabling a more comprehensive understanding of the multifaceted impact of PAC. This approach offered a comprehensive perspective on the data, where observed patterns in numerical results could be explained through the additional insights provided by carers' personal reflections. It recognises the significance of understanding not only the impact of PAC upon carers' experiences but how they view this impact within the dementia diagnosis journey, resulting in a more thorough exploration of the role that PAC plays in supporting dementia care.

Results

Preliminary analyses were conducted to determine whether significant demographic differences existed between the PAC and non-PAC groups. An independent samples t-test indicated that carers in the PAC group (M = 70, SD = 13) were significantly older than those in the non-PAC group (M = 65, SD = 12), t(128) = 2.22, p = .028, d = 0.39. A chi-square test of independence revealed no significant association between group and gender, $\chi^2(1) = 0.37$, p = .542. Similarly, there were no significant differences between groups for education level, $\chi^2(4) = 3.40$, p = .493. However, a significant association was observed between group and relationship to the person with dementia, $\chi^2(1) = 4.28$, p = .039, suggesting that carers in the PAC group were more likely to be spouses or partners of the person with dementia than those in the non-PAC group.

Although this study examined two outcome variables, ANOVA and ANCOVA were not used. Independent samples t-tests were appropriate for comparing the two groups. ANCOVA was considered to adjust for potential confounders such as age or relationship to the person with dementia; however, the study was not powered for multivariate analysis, and most demographic variables were categorical. While a significant group difference was observed in relationship status, no differences were found in gender or education. Therefore, t-tests were retained as the most suitable method given the study design and sample size.

Table 14 shows the descriptive statistics output capturing the experience and well-being scores of both groups, summarising the mean, standard deviation and minimum and maximum scores. The data focusing on experience and well-being scores are shown in Tables 14 and 15 to illustrate critical findings from the *t*-tests, which deliver direct insights into the influence of PAC.

Table 14

Descriptive Statistics

	Total Experience Score		Total WEMWBS Score	
	PAC	non-PAC	PAC	non-PAC
Valid	65	65	65	65
Missing	0	0	0	0
Mean	77.83	72.31	47.77	34.25
Std. Deviation	6.99	16.40	8.49	9.63
Minimum	57.00	47.00	30.00	14.00
Maximum	91.00	115.00	64.00	64.00

Independent samples *t*-tests were conducted to compare the overall initial appointment experiences and well-being scores between the two groups. Results indicated significantly higher scores for initial appointment experiences and wellbeing in the PAC group as compared with the non-PAC group, as illustrated in Table 15. Elevated well-being scores were seen across all items, indicating that PAC may significantly contribute to improving both the caregiving experience and the psychological well-being of carers.

Table 15

Independent Samples T-Test for Experience and WEMWBS Scores

	t	*df*	PAC M (*SD*)	Non-PAC M (*SD*)	*p*	*d*	*SE*
Total Experience Score	2.5	128	47.77 (*8.49*)	72.21 (*16.40*)	0.01	0.44	0.18
Total WEMWBS Score	8.5	128	50.55 (*7.25*)	34.25 (*9.63*)	< .01	1.49	0.22

Figure 3 shows a box and whisker plot illustrating the distribution of initial experience scores between the PAC and non-PAC groups, whilst Figure 4 illustrates the distribution of WEMWBS scores. The box signifies the interquartile range (IQR; 25th – 7th percentile), horizontal lines represent the median values, and the whiskers represent the highest and lowest values within 1.5 times the IQR from the upper and lower quartiles. Figure 3 shows that the median score of the PAC group was 78, as compared with the non-PAC group, where the median score was 68. Figure 3 also demonstrates that both groups had outliers, suggesting some variability in individual responses. Figure 4 shows the distribution of the WEMWBS scores of both groups, where the median score of the PAC group was 50, compared with 32 for the non-PAC group, the latter demonstrating an outlier, represented as an individual point beyond the whiskers.

Figure 3

Boxplot of Initial Appointment Experience Scores by Group

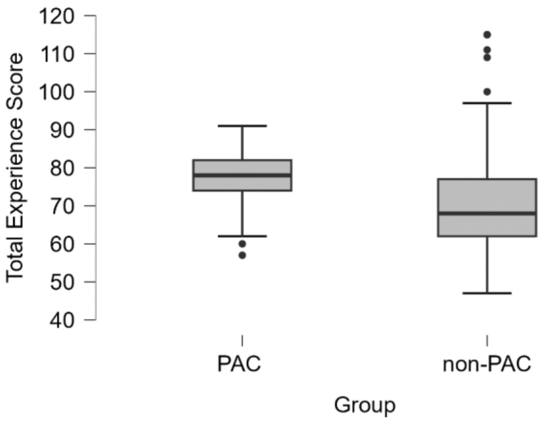
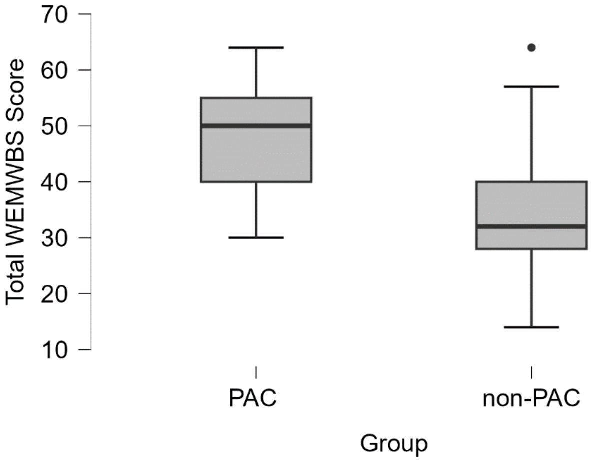


Figure 4

Boxplot of WEMWBS Scores By Group



Thematic Analysis of Carer Feedback

Although quantitative data provides significant insight into carer well-being and experiences of the initial appointment, they do not provide the nuanced, contextual components of the interactions the carers had with the memory assessment service. Thematic analysis, as described by Braun and Clarke (2006), was used to examine the data in this study owing to flexibility in identifying and analysing patterns across a diverse data set. Thematic analysis is appropriate for use in exploratory data as it is not confined to established theoretical frameworks, and through theme identification, it highlights the participants' experiences using their own words (Braun & Clarke, 2012). These subjective experiences of carers from the initial appointment endeavour to provide context to the quantitative findings to provide a more holistic understanding of how this impacted upon carers' satisfaction and well-being. Table 16 portrays the themes and supporting quotes for each group of carers.

Table 16

Themes and Supporting Quotes for Carers Who Received and Did Not Receive PAC

Group	Theme	Supporting Quotes
Carers Who Received PAC	Clear Communication and Information	“The appointment with the nurse was very helpful as it meant we went into it with eyes wide open.” “The clinician clearly explained what would happen during the assessment, and I felt like I understood everything.” “Very useful and informative.”
	Emotional Support and Reassurance	“The nurse was very matter-of-fact yet very kind and sympathetic and made us feel less worried.” “The nurse really listened to me and I felt like my contribution was valued.” “The nurses made me feel confident to look after my husband, and so far, it is okay.”
	Preparedness and Confidence	“The appointment gave me the confidence that we were doing the right thing.” “I felt prepared for what was going to happen next, which made me less anxious.” “It was reassuring to know what to expect and how to handle it.”
Carers Who Did Not Receive PAC	Lack of Information and Support	“I left with more questions than answers.” “We basically left this appointment with a dementia diagnosis which we had hoped would be explained by something else as well as a few leaflets.” “The process was not explained well and we felt lost.”

Group	Theme	Supporting Quotes
	Emotional Distress and Isolation	“The appointment felt very impersonal. I’m sure that the nurse has done these appointments many times before, but it was the first time for us.” “I felt that we were just another number, not people with unique needs.” “The overall experience was overwhelming and confusing.”
	Challenges in Communication	“I would have liked more time to be able to ask questions.” “The nurse didn’t really answer my questions about dementia very confidently.” “It felt like they were rushing through everything without really listening to us.”

Discussion

The present study aimed to investigate how PAC affects carers’ experiences by combining both quantitative data and the personal accounts of carers to assess the efficacy of PAC interventions. It was hypothesised that carers within the PAC group would have higher experience and well-being scores than those from the non-PAC group, which is supported by findings of this study. They propose that receiving a PAC appointment enables not just satisfaction with this early stage of the diagnosis journey but impacts upon their well-being following diagnosis, suggesting that PAC is potentially a critical intervention within the dementia care pathway for carers. These results are supported by previous studies, which note that emotional readiness and supportive conversations are critical in reducing the psychological burden of carers along the dementia care pathway (Ng et al., 2021; Samsi & Manthorpe, 2013). This research adds to such studies by demonstrating the observable impact of PAC appointments in improving the outcomes of carers of people with dementia through the direct comparison of the PAC and non-PAC groups. These findings demonstrate the importance of a structured yet flexible approach to PAC that can be adapted to carers’ varied needs. This study suggests that introducing PAC as a routine intervention in dementia care could lead to broader improvements across the healthcare system by reducing carer burden, which has implications for both clinical practice and policy development.

Quantitative Findings

This study employed a mixed-methods approach to develop a holistic understanding of the experience of the initial appointment within a memory assessment service following a referral from a GP from the view of carers. The quantitative component was analysed using *t*-tests, which showed that carers who had received a PAC appointment had significantly more positive experiences than those who had not. However, other contextual factors could have influenced the results, such as the relationship between the person with dementia and the carer or the perceived level of support that is expected from PAC. This evidence supports the proposition that PAC should provide customised care and tailor its approach to meet the individual requirements of the carers. Former studies note the importance of unambiguous and empathetic communication within healthcare settings, especially in emotionally challenging contexts such as dementia care (Foley et al., 2017), which the findings of this study support further.

Participants within the PAC group reported higher satisfaction scores across all items of the initial appointment questionnaire as compared with the non-PAC group, including items concerning understanding the process of diagnosis, believing that the healthcare professional valued what they had to say and feeling listened to. This supports the approach of PAC, which endeavours to facilitate collaborative interactions between carers and healthcare professionals. Additionally, this improves the dementia diagnosis journey, which is recognised as a stressful experience (Keady & Gilliard, 2002; Samsi et al., 2013). This further supports the results found in the systematic literature review in Chapter 2, which found that PAC enabled carers to feel prepared for a diagnosis of dementia. Being in receipt of clear and comprehensive information reduces uncertainty and stress (Foley et al., 2017) and carers are encouraged to work collaboratively with those they care for and healthcare professionals through PAC, enabling them to feel supported (Gridley & Parker, 2022). The well-being scores are a particularly notable finding, as illustrated in Table 14. The higher scores reflect her levels of perceived well-being, and previous studies have found a high correlation between the WEMWBS and validated depression scales such as the Center for Epidemiologic Studies Depression (CES-D) scale (Powell et al., 2013), meaning that scores can be interpreted within ranges that suggest different levels of depressive symptoms (Tennant et al., 2007). The participants within the non-PAC group reported well-being scores that were typically associated with possible or probable depression. Conversely, whilst participants in the PAC group did not report scores that suggested excellent well-being, they were significantly higher than those found within the non-PAC group, proposing less likelihood of experiencing depressive symptoms. This demonstrates that PAC may have the potential to safeguard carers' well-being by possibly lowering the risk of depression (Maheswaran et al., 2012; Powell et al., 2013; Tennant et al., 2007). This is particularly important as it suggests that the beneficial components of PAC could potentially extend past the initial appointment within the memory assessment service and beyond receiving a diagnosis of dementia, possibly enabling a level of sustained well-being in carers. This is because carers are more likely to develop anxiety and depression due to the stress that comes with taking care of a person with dementia (Andrén & Elmståhl, 2005) and may explain why the WEMWBS scores for the participants in the PAC group were also higher. This may suggest that early interventions such as counselling can help carers build the psychological resources they need to look after those they care for.

When comparing these findings with existing literature, it is important to acknowledge key methodological differences that may account for variation in the findings of this study. For example, some studies evaluating carer interventions focus on longer-term outcomes or use randomised controlled trial designs, while this study used a quasi-experimental design with self-selected groups. This design may have introduced selection bias, particularly as carers in the PAC group were recruited through a service known to offer the intervention routinely, which may have attracted individuals who were already more engaged or motivated to seek support. In addition, demographic differences between the PAC and non-PAC groups, as outlined in Table 13, may have influenced the outcomes. Variations such as age, gender, and the nature of the relationship to the person with dementia could each effect wellbeing scores and experiences of diagnostic services independently of PAC. These differences were not controlled for statistically in the analysis which limits the extent to which the observed group differences can be attributed to the intervention alone. Although the groups were broadly comparable across most demographic variables, a significant age difference was found, with carers in the PAC group being older on average. This may have influenced the results, as older carers might differ in their expectations or emotional responses to dementia services. However, given the exploratory nature of this study and the limited power for covariate analysis, age was not statistically controlled.

The distribution of WEMWBS scores within the PAC group was less variable than the control group, further highlighting the standardising effect of PAC on carers' mental well-being. Previous research suggests that dedicated spaces where carers felt listened to and could participate in discussions before clinical appointments can increase their emotional stability (Smith et al., 2015). This supports the use of interventions such as PAC that seeks to provide carers with access to structured support early on in the dementia diagnosis journey to positively impact upon well-being (Bayly et al., 2021). In contrast, the broader range of scores in the non-PAC group may indicate that the absence of structured support may lead to more significant disparities in mental well-being, with some carers experiencing significantly lower levels of mental health. The higher WEMWBS scores among the PAC group align with theories of psychological resilience (Blodgett et al., 2022), suggesting that PAC may help build carers' capacity to cope with stress and uncertainty. PAC may reduce feelings of helplessness by providing carers with information, emotional support, and practical advice before the diagnostic process (Oliveira et al., 2019) and increase carers' confidence in managing their role. This is particularly important given the cumulative stress that many carers experience, which can lead to burnout, depression, and physical health problems if not adequately managed (Pinquart & Sörensen, 2003).

The impact of PAC on the well-being of carers and family dynamics can be explained using the Family Systems Illness Model (FSIM; Rolland, 1994). The FSIM acknowledges that receiving a diagnosis impacts not just the person living with the condition but also their families and as family members frequently take the form of carers (NICE, 2018) who frequently endure the emotional and physical strain of caring (Rolland, 1994). The personalised, practical strategies and informational and emotional support provided to carers through PAC appointments aid them in coping with the challenges that can accompany a diagnosis of dementia by enabling their readiness and perseverance (Rolland, 1994). PAC assists this by fostering a more balanced and supportive family system that increases feelings of capability and confidence in caring roles. This approach correlates with the importance the FSIM model places on family adaptation and resilience. It suggests that positive and cohesive environments for people with dementia and their carers are created through interventions such as PAC, resulting in more positive caring outcomes.

The findings from this study have some practical implications should PAC be an intervention that is considered for wider implementation in dementia care pathways. For carers, communication would be more standardised resulting in more structured support and increased well-being. For healthcare professionals, there would be a need for further training and potentially service remodelling to include it as standard care to ensure consistent delivery. Moreover, this approach aligns with the theory by creating a healthcare environment that not only addresses immediate diagnostic needs but also strengthens carers' resilience and capacity for effective caregiving in the long term.

Furthermore, the positive impact of PAC on mental well-being may have ripple effects beyond the immediate diagnostic process. Outcomes for people with dementia are improved as they receive more effective care when carers feel well-supported (Thompson et al., 2007). Enhancing carer well-being through interventions such as PAC is essential due to their critical role in dementia management (Brodaty & Donkin, 2009).

Qualitative Findings

Table 16 shows the themes noted in the qualitative data. Carers in the PAC group reported more positive experiences, characterised by three themes, including (1) clear communication and information, (2) emotional support and reassurance, and (3) preparedness and confidence. These aligned with the quantitative results, which revealed that the participants in the PAC group provided statistically significant higher satisfaction scores with the initial appointment, thus implying that PAC might be effective in meeting the informational and emotional needs of the carers. In contrast, the themes found in the qualitative data from the non-PAC group were mostly negative. Three themes were found which were (1) lack of information and support, (2) emotional distress and isolation, and (3) challenges in communication. Insufficient information appears to be consistently discussed and this demonstrates the importance that carers place on clear, personalised communication throughout the dementia diagnosis journey. Carers reported feeling isolated and unprepared, suggesting that care without PAC may inadequately support carers during a critical adjustment period.

The qualitative data emphasise the need for a more personalised and supportive approach to the dementia diagnosis journey. PAC seems to help alleviate a number of difficulties faced by carers of people with dementia through the provision of safe, open environments that facilitate conversations where questions can be asked, concerns addressed, and personalised information can be given. Carer experiences are found to be more positive through individualised support approaches which enables them to clearly understand the journey to diagnosis and appears to empower them in caring for a person with dementia as evidenced through the qualitative findings. PAC was demonstrated to provide emotional reassurance through the delivery of clear information provision that results in carers feeling emotionally prepared for the journey to diagnosis and beyond.

Implications for Practice

Based upon the significant differences in the scores of the PAC and non-PAC groups in their experiences of the initial appointment and their well-being, PAC should be considered for incorporation into usual care practices at an early stage of the dementia care pathway. Benefits to carers appeared more equally distributed to carers within the PAC group demonstrated by the higher means and little variation of scores. Dementia is often an emotionally charged topic of conversation and requires addressing in a sensitive and supportive way (Tuijt et al., 2021). Although the results of this study appear to recommend the implementation of PAC into usual care, it is imperative to be mindful of the practicalities of its application. Firstly, memory assessment services and any other organisation that could deliver PAC must ensure that not only are staff adequately trained to provide the service, but that sufficient resources are available to ensure consistent support. Secondly, PAC must be continually evaluated and reconfigured to ensure that it remains to be effective and flexible enough to respond to the changing needs of those it is designed to assist.

The qualitative data highlight the importance of integrating PAC into dementia care practices to better support carers. PAC appears to improve the immediate experiences of carers by providing them with the knowledge and confidence required for their ongoing caring role by meeting their needs for personalised information and emotional support. As such, consideration should be given to expanding access to PAC and improving how it is presently delivered so that more carers can receive its benefits and support someone experiencing cognitive decline throughout their dementia journey more effectively.

Limitations and Future Research

Though this study appears to have some considerable strengths, it needs to address a number of limitations. One possible limitation is that there was a difference in how participants were recruited. The participants recruited for the PAC group were contacted by an assistant psychologist from the team who had conducted their PAC appointments by sending letters inviting them to the study. Conversely, the participants in the non-PAC group were obtained from the JDR website and include people who have already expressed their willingness to participate in research. This means that the different recruitment methods may have led to some minor differences in the motivational and engagement levels. For example, participants who were recruited through the assistant psychologist from the team who delivered their PAC appointments could have viewed participation as potentially being an extension of their care (Newington & Metcalfe, 2014). The participants whom the research team recruited through the JDR website may have been more self-selecting with an interest in contributing to research, which is the purpose of JDR, to encourage people with dementia and carers to register with them. Much literature exists to support the influence of recruitment on participant behaviours and how this can impact upon study outcomes (Brutus et al., 2013; Kannan et al., 2019; Tripepi et al., 2010). Therefore, there is the potential for differences in attitudes to contributing in studies which requires consideration when determining the findings. These different participant profiles could result from using different recruitment approaches which can potentially affect generalisability (Manohar et al., 2018; Newington & Metcalfe, 2014). Further research can remedy this limitation by standardising the methods used in participant recruitment, such as recruiting from multiple NHS Trusts, as PAC is not a commonly used intervention within the dementia care pathway. In this way, bias associated with participant engagement and motivation is reduced (Domecq et al., 2014). Furthermore, to assess whether the differences observed in outcomes are owed to the influence of PAC or differences in recruitment methods, characteristics such as demographics could be used to match participants and improve comparability between groups and the robustness of the investigation.

As noted in Chapter 5, the inconsistency in the approach and delivery of PAC by healthcare professionals caused some challenges in this study. Despite the healthcare professionals speaking passionately about PAC in Chapter 4, it was shown in Chapter 5 that the variability in delivery means that there was a degree of irregularity in carer experiences.

Whilst variability is an important component of PAC's flexible, patient-centred stance, it should not be ambiguous, and a framework is critical to ensure that training and processes are consistently delivered. Recognising this challenge has deepened the understanding of the research process by highlighting the balance required between standardisation for comparability and adaptability to individual needs.

It should also be noted that there is no universal approach to conducting PAC, something that was discussed in Chapter 5. Whilst the clinicians have a set of questions that they are advised to ask as part of the process of the PAC appointment, each clinician employs their own interpretation of what quality PAC looks like and what it should entail. Developing a 'gold standard' clinical framework would facilitate excellent provision of PAC and guarantee consistent quality for people with dementia and their carers. Moreover, investigating the cost-effectiveness of PAC could yield vital information for healthcare professionals and policymakers as they consider its wider implementation.

Although the number of participants was calculated accordingly using power analysis, it is possible that it restricts the generalisability of the study's findings to broader populations. By recruiting from larger, more diverse populations, further studies could enable a more comprehensive understanding of the impact of PAC. Addressing these limitations, future research could adopt mixed-methods approaches, integrating quantitative assessments with qualitative interviews to gain deeper insights into carers' experiences. The potential long-term benefits of PAC on the mental well-being of carers seem promising, but they necessitate further exploration.

It is important to note that participants' support needs may have increased between the initial appointment and completing the study. The participants received their initial appointment within the memory assessment service between 2022 and 2024. As such, consideration is required as to whether and how the benefits of PAC may be sustained over time and how PAC influences care provision at different dementia stages. In addition, particular aspects of the experience of carers could be explored to understand how PAC enhances well-being. Research should also evaluate the effects of PAC on different populations to ensure that the intervention is relevant and valuable for all groups of carers as socioeconomic status and cultural factors impact access to timely diagnoses (Kerwin et al., 2022).

The present study’s findings suggest that carers significantly benefit from PAC appointments. However, further studies are required to understand how PAC affects particular subgroups within carer populations, such as younger versus older carers or those with different levels of prior knowledge, which could inform specialised approaches that better meet diverse needs. Addressing these matters would strengthen the evidence base and offer a clearer pathway for PAC implementation in dementia care services.

Conclusion

The findings from this study suggest that providing PAC appointments to carers of people with dementia at the early stages of the diagnosis journey can significantly impact the initial appointment within the memory assessment service where they meet specialist healthcare practitioners for the first time and that this may affect their well-being in the long-term. Findings from the quantitative component of the study demonstrated higher satisfaction scores from the initial appointment and in well-being from participants in the PAC group. The qualitative findings correlated with these and noted themes suggesting that PAC addressed carers’ needs for clear information and communication, emotional support and reassurance, and feeling confident and prepared, resulting in a better experience of the dementia care pathway than carers who had not received PAC. Owing to the evidence suggesting the benefits and effectiveness of PAC in enabling experience and well-being, its implementation into the dementia care pathway should be considered. Further research is required to assess the impact of PAC within diverse carer populations and determine the impact of the long-term benefits of PAC for carers. Guaranteeing consistency of PAC delivery whilst providing a person-centred approach that meets the needs of carers is essential to improving the quality of dementia care provision and its outcomes for both people with dementia and those who care for them.

Chapter 7: Thesis Conclusion

This thesis has critiqued the role of PAC within dementia care pathways and how its approach and application affects those with dementia, their carers and the healthcare professionals who deliver it. This research is constructed of five studies. The first was a systematic literature review that employed a qualitative synthesis of empirical research on PAC in dementia care pathways. The second was a service evaluation that employed quantitative methods to examine how the characteristics of people who had experienced PAC appointments affected diagnosis outcomes. The third was an exploratory study that sought the views of healthcare professionals on PAC through semi-structured interviews. The fourth was an experimental study to assess the efficacy of PAC in reducing psychological distress in people with dementia. Finally, the fifth was a mixed-methods study to determine the effects of PAC on carers' experiences of the first appointment with the memory assessment service and their psychological well-being post-diagnosis. When combined, these methodologies deliver a holistic understanding of the strengths, limitations and implications of PAC upon clinical practice and dementia care policies. Chapter 7 integrates the fundamental findings from the preceding chapters and critically analyses how these contribute to existing knowledge, and highlights themes that have appeared consistently throughout the thesis. Finally, it discusses the broader implications of PAC for dementia care pathways and outlines considerations for further research where PAC has the potential to evolve to respond to the gaps and challenges identified within the former chapters of this thesis.

Overview of Findings

The systematic literature review in Chapter 2 demonstrated that PAC plays a unique and significant role in helping people experiencing cognitive decline feel prepared to receive a diagnosis of dementia. Despite the relatively limited scope of existing literature, PAC was consistently recognised as an essential element of dementia care. The review demonstrated that PAC helps people with dementia psychologically adjust to the possibility of receiving a diagnosis by providing early support and managing expectations. Furthermore, PAC offers carers the opportunity to discuss concerns and enables confidence in healthcare professionals to deliver sensitive and potentially distressing diagnoses. Such findings demonstrate how important PAC is in alleviating the psychological challenges that accompany diagnoses of dementia, aiding those experiencing cognitive decline and those who care for them to journey through the uncertainty associated with the process of diagnosis.

However, the systematic review noted some significant limitations, especially concerning the cultural and geographical gaps. This is because the studies took place in the UK, meaning that PAC may not apply to non-Western cultures. It is known that some ethnic groups view dementia as being a spiritual or moral issue or a natural process of ageing and, therefore, not a medical condition that requires management through intervention and support (Gerritsen et al., 2018). These differing perceptions of dementia will likely affect how families approach diagnosis and care, suggesting that it is unknown if PAC models developed in Western contexts are able to be directly transferable to other cultural environments. Furthermore, there was a notable lack of research on how various healthcare systems influence PAC delivery. For instance, in the UK, the NHS is centrally managed and operated compared with services in the United States, which are decentralised, and therefore, more research is required to establish how the concept of PAC can be implemented and yet still be effective across different cultures and health care systems (Sreeramareddy & Sathyanarayana, 2019).

It is also essential to be mindful of the variability of PAC within different settings within the same country. Chapter 4 recommends the possibility of implementing PAC within the services provided by the Alzheimer's Society and other structured organisations that deliver dementia care. This thesis has repeatedly noted the inconsistency of PAC delivery which is the result of experience, the time a healthcare professional has available, the subjective regard held towards PAC, and the lack of a clinical framework that would standardise its approach and aid its delivery and benefits. Healthcare professionals may be more skilled in enabling the sensitive conversations that are needed for PAC to be most effective, as compared to those with less experience and may be less adept at providing the same level of support. The systematic review closed by discussing the need for a standardised framework of PAC that can be consistently implemented across a diverse number of healthcare settings where all people with dementia and their carers can access care.

Chapter 3 consisted of a service evaluation, which provided additional insights by investigating variables such as gender, age, and ethnicity and their interplay with the demographic characteristics of people with dementia. Previous literature supported results that demonstrated women as being at a higher risk of developing Alzheimer's Disease, potentially due to their longer life expectancy (Andrew & Tierney, 2018). Similarly, literature supported the findings of the correlation between age and the probability of receiving a dementia diagnosis (Corrada et al., 2020). However, disparities were noted in diagnosis outcomes, especially with regard to ethnicity and the relationship between people with dementia and their primary carer. People belonging to ethnic groups were less likely to proceed to assessment and receive a dementia diagnosis, suggesting that experiences of the dementia care pathway are heavily influenced by cultural and systemic factors (Tsamakis et al., 2021).

The relationship between the person with dementia and their primary carer is important as results showed that people with dementia were significantly more likely to consent to proceed to an assessment and receive a diagnosis when supported by their spouses or partners, as compared to those with other family members or professional carers. This particular finding demonstrates the importance of receiving practical and emotional support in the decision-making process for people with dementia (Kotagal et al., 2015). It raises important concerns about the adequacy of support for individuals without close family ties, as they may be at greater risk of declining assessments, thereby missing out on early interventions that could improve their quality of life. The evaluation reveals that it is important for PAC to involve not only people with dementia but also those who care for them in order to design and deliver PAC in a way that can be understood and that they are able to navigate. Future research needs to consider how carers from diverse populations understand and engage with PAC and the impact this can have on how PAC is delivered. Similarly, it would be useful to understand how people with dementia from ethnic groups are able to obtain similar benefits to others.

The qualitative study in Chapter 4 provided unique insights into the effectiveness of PAC and how it is delivered according to the healthcare professionals who implement it as part of the usual care provision for people with dementia and their carers. The data was collected by semi-structured interviews and reflexive thematic analysis yielded three major themes. Firstly, the person with dementia was placed at the centre of their diagnostic journey through PAC. Secondly, PAC enabled candid conversations to take place, resulting in strong therapeutic alliances being built. Lastly, through PAC provision, the person with dementia realises that they are more than their diagnosis. These themes demonstrate how PAC enables timely, patient-centred diagnoses that reinforce feelings of autonomy of people with dementia.

The healthcare professionals who participated in this study continuously spoke about how they felt that PAC empowers people with dementia by returning a sense of agency and supporting them in making informed choices concerning their care. Loss of autonomy is extremely concerning for many people who live with dementia, particularly as their condition progresses (Merl et al., 2022), and therefore, such empowerment is especially valuable. For individuals who do not feel ready to proceed with an assessment for dementia after PAC, there is currently no ongoing support offered within the memory service. Instead, they are discharged from the diagnostic pathway and advised to recontact their GP should they wish to be reassessed in the future. This absence of follow-up support can leave individuals and their families without guidance at a time of uncertainty, potentially delaying future access to diagnosis and care.

In some cases, delays in support or a lack of follow-up may result in further cognitive deterioration, which raises the risk of capacity loss to make decisions about assessment or treatment. This highlights the importance of providing timely and proactive support through interventions such as PAC to ensure people are supported to make decisions while they still have the capacity to do so. Although the healthcare professionals held PAC in high regard owing to its perceived benefits to all within the triadic relationship, they acknowledged the systemic pressures to obtain target diagnosis numbers. The healthcare professionals discussed the tension of early versus timely diagnoses, where they preferred the latter, feeling that they aligned more with person-centred care. The healthcare professionals frequently mentioned that although quick diagnoses address the NHS goals of efficiency, such processes have the potential to cause harm should the psychological and emotional needs of people with dementia not be sufficiently met.

This study also revealed that different healthcare professionals deliver PAC in different ways. PAC is meant to encourage the person with dementia and their carer to communicate freely. However, some of the healthcare professionals remarked that while some generate open and transparent discussions, others preferred taking it slowly and being more subtle, especially where they had to discuss certain aspects that may be uncomfortable for the patient, such as the possible outcome of the assessment, for example. Therefore, whilst PAC may still be a beneficial service, questions arise as to whether all people with dementia and their carers encounter the same quality of care, irrespective of the healthcare professional delivering the appointment. The study concluded by discussing the requirement of further training and support for all healthcare professionals who deliver PAC to guarantee effectiveness and consistency that focused on balancing the requirement for timely diagnoses whilst ensuring a person-centred approach (Watson et al., 2018).

The impact of PAC on people with dementia was investigated in Chapter 5 by exploring how certain psychological factors of well-being were affected including fear of dementia, depression, anxiety and stress. Results showed that PAC significantly reduced stress levels and enabled clarity during the diagnosis journey. These findings strengthen the case for PAC to be routinely offered to all carers of people with dementia as they provide clear indications that the intervention is not only well received but also has a measurable and positive impact on carers' experiences of care and psychological wellbeing. Although this study included a comparison group of carers who did not receive PAC, the design was not randomised, and group allocation was based on existing service structures rather than experimental assignment. This introduces the possibility of selection bias or unmeasured differences between groups that could have influenced the outcomes. As such, while the findings are promising, they should be interpreted cautiously. By unpacking, exploring and addressing worries and uncertainties early on in the dementia care pathway, PAC enables feelings of control in people with dementia, which can reduce some of the immediate psychological challenges that relate to the diagnosis journey (Aminzadeh et al., 2007).

Despite the perceived impact of PAC upon stress levels, other areas, such as fear of dementia, depression and anxiety, experienced little change. Some people with dementia experienced reduced scores, but these were not statistically significant. Therefore, this inconsistency proposes that although PAC may assist in alleviating immediate feelings of stress towards the diagnosis journey, it may not meet the more persistent worries and concerns that people with dementia have, such as what the future could bring (Ostwald et al., 2002) or anxieties of what implications a diagnosis of dementia will have upon their lives (Milby et al., 2017).

One of the key limitations of the study was the variability in PAC delivery, which likely influenced the mixed results. It was also partly this that led to the early termination of the study, with a person with dementia and their carer being upset by the questions and feeling that they could not then properly discuss the feelings that came about as the PAC they had received had been minimal from that clinician as compared to how other healthcare professionals deliver their sessions.

This study also considered it necessary to develop a standardised approach to PAC where people with dementia would receive consistent support provision. Furthermore, the cross-sectional design of the study meant that only a glimpse is provided of how people with dementia experience PAC, meaning that it is not possible to determine conclusions on the impact of longer-term effects on well-being. Further studies are required to explore if PAC impacts people with dementia beyond diagnosis, which could be captured through longitudinal studies to observe if and how well-being is sustained across the various stages of dementia. For PAC to be adopted as a standard component of dementia care, it would need to be formally recognised within clinical practice guidelines. In England and Wales, these are developed by the National Institute for Health and Care Excellence (NICE), whose recommendations inform commissioning and service delivery across the NHS. In addition, local implementation would likely involve Integrated Care Boards (ICBs), who are responsible for commissioning and overseeing service provision in their regions.

Chapter 6 explored how PAC impacted upon the experiences and well-being of carers of people with dementia by comparing these with those who had not received a PAC appointment. The findings in this study showed significant differences in the experiences of the initial appointment in the memory assessment service and overall well-being between the two groups. Carers who had been in receipt of PAC reported significantly better outcomes, where results revealed that they felt emotionally prepared for the challenges of caring for someone with dementia. Carers in the PAC group felt that PAC had fostered the informational and emotional support required to meet the nuanced dynamics of caring for a person with dementia.

Carers who received a PAC appointment noted that PAC enabled them to manage the emotional challenges of the caring role, especially in the earlier stages of the diagnosis journey, as it provided them with an environment to ask questions, raise concerns and understand dementia. This increased understanding not only helped reduce the emotional burden but also enhanced their capacity to provide informed care, ultimately improving the overall well-being of both the carer and the person with dementia.

However, the study also highlighted variability in carers' experiences, particularly concerning the quality and accessibility of PAC services. Some carers in the non-PAC group felt that they had received insufficient or inconsistent support. This further demonstrates that PAC services need to be developed into a more comprehensive and standardised approach that enables consistent delivery by healthcare professionals to all carers regardless of their location or the resources that are available to them.

Similarly to Chapter 5, this study noted that further research should be conducted to explore the long-term benefits of PAC appointments for carers. Despite the promising results of this study in demonstrating the short-term benefits for carers, it is unknown if these are sustainable over time as the participants of the study had been caring for a person with dementia for no longer than 2 years from diagnosis. As dementia progresses, so too do the challenges faced by carers (Garcia-Martin et al., 2023) and therefore, further research could help to understand if some of the essential components of PAC are able to be integrated into other interventions that support carers.

Empowerment and Autonomy of People with Dementia

One of the most prominent themes throughout the thesis is the role of PAC in empowering people with dementia by restoring their autonomy and facilitating their active participation in the diagnostic and care process, as noted in Chapters 3 and 4. Loss of cognitive and decision-making abilities correlated with a person's stage of dementia (Darby & Dickerson, 2017), and PAC provides people with dementia with the opportunity to regain a sense of control at a time when it may feel as though control is being lost. People with dementia still have the cognitive ability to make informed choices concerning their care within the early stages of the condition (Hoffman et al., 2014), which is why empowerment is so especially important. PAC enables this by ensuring that people with dementia are provided clear information about the diagnosis journey and the options available for their care in a format that is accessible to them.

The challenge being faced is that it is crucial to ensure that these opportunities for empowerment are also available to everyone with dementia, irrespective of their cultural background or socioeconomic status. This thesis has focused on the idea that the heterogeneity of PAC poses a risk to the extent to which it can enhance the autonomy of people with dementia, particularly those from ethnic minorities. Ethnic minority populations and non-Western societies may not encounter the same extent of the benefits provided by PAC should it not be adapted to sensitively address specific cultural and healthcare contexts.

In turn, this then raises essential questions as to how to improve the accessibility and inclusivity of PAC (c.f. Rathod et al., 2019).

These findings highlight the emotional and psychological benefits that carers derive from PAC, particularly in terms of increased confidence, preparedness, and emotional support during what is often a distressing and uncertain time. By feeling more equipped to support their loved one, carers may experience a greater sense of control and reduced burden, which can positively influence the dynamics of the caregiving relationship. These improvements are not only beneficial to the carers themselves but may also enhance the care experience for the person with dementia. Importantly, these outcomes reflect key principles of person-centred care, including the recognition of carers as partners in care, the emphasis on relational support, and the tailoring of interventions to individual needs and values (Kitwood, 1997; Brooker, 2004; NICE, 2018). PAC, by equipping carers with the tools and emotional readiness to support someone through diagnosis and beyond, embodies these principles in practice.

Additionally, although PAC appears to empower people with dementia throughout the diagnosis journey, the long-term impact of PAC on perceived and actual autonomy across the stages of dementia should be further investigated. By combining support such as advocates and legal counselling with PAC, it might be possible for people with dementia to feel a sense of autonomy throughout their dementia journey.

Communication

Open, honest, and transparent communication between healthcare professionals, people with dementia, and their carers is a recurring theme in the thesis and is identified as a key factor in the success of PAC, as found in Chapters 2, 3 and 6, especially. This communication quality depends on the ability of PAC to reduce myths and misconceptions that are associated with dementia and to listen to and respond to worries and concerns, thus promoting the formation of therapeutic alliances. Open and honest discussions in a safe and sensitive environment help both those living with dementia and their carers to learn more about the condition and how it progresses and also encourage asking any important questions that they may have. Concerns are raised, however, regarding the variability in PAC delivery and whether all people with dementia and their carers can access the same level of communicated support. Chapter 4 mentions how some of the healthcare professionals interviewed on their perspectives on the key components and clinical effectiveness of PAC approach sensitive topics such as diagnosis using a more cautious approach compared to others who believe that open and transparent communication benefits all within the triadic relationship. This inconsistency could have a significant impact (National Council for the Professional Development of Nursing and Midwifery, 2006) on the experiences of people with dementia and carers, particularly in how well-prepared they feel for the diagnosis and subsequent care process. Communication in PAC requires a standardised practice to ensure that all people with dementia and their carers benefit from dialogue that is honest, open and supportive, irrespective of the particular healthcare professional conducting the appointment or the healthcare setting within which PAC is held, something that is noted in Chapters 4 and 5.

Furthermore, this thesis has called attention to the significance of cultural competence in communication. It is essential that healthcare professionals who conduct PAC within culturally diverse populations have a sound understanding of how different cultural groups perceive dementia to ensure optimal communication (Fletcher, 2020; Gerritsen et al., 2018), as these perceptions play a significant role in their willingness to engage with the dementia care pathway. Further studies should determine how PAC could develop and improve culturally sensitive communication to ensure that it respects and responds to the diverse cultures and values of people living with dementia and their families.

Cultural Sensitivity

Somewhat overlapping with the theme of communication is cultural sensitivity, which appeared as a significant and continual theme throughout this thesis, especially within Chapters 3, 5 and 6 surrounding the disparities in dementia diagnosis and care outcomes across different ethnic groups. This thesis recognises that the majority of PAC models and the research surrounding it, especially in dementia care pathways, has been conducted in Western cultures where dementia is viewed as a clinical condition which is diagnosed and treated. Conversely, many non-Western cultures may have different views, seeing dementia as a natural aspect of ageing or as a spiritual or ethical concern (Fletcher, 2020; Gerritsen et al., 2018). There is a significant interplay between culture and how people with dementia and their carers view dementia and support services (Brijnath et al., 2022; La Fontaine et al., 2007).

Research that examines how PAC is received across multiple cultures is lacking, and therefore, it is unknown how well it meets the needs of non-Western populations in dementia care. For instance, if, in certain cultures, dementia is not well understood and there is a stigma associated with it, then a person with dementia will not readily participate in PAC, much less be assessed for dementia. Furthermore, barriers to support may be experienced by those who would step into caring roles from these communities (Brijnath et al., 2022).

This thesis recommends that further research is conducted to evaluate the appropriateness and acceptability of PAC in ethnic groups, but specifically, to shape its approach to ensure that it is culturally sensitive to the needs of those it seeks to support across different cultures and healthcare services. This may involve tailoring the content and the way PAC is delivered to be relevant to cultural and religious backgrounds and healthcare services of different communities.

The development and delivery of PAC should be underpinned by a commitment to co-production, ensuring that the voices of people with dementia and their carers inform both content and implementation. Co-production helps ensure that PAC is not only clinically effective but also culturally and contextually relevant to the communities it serves. By actively involving people with lived experience, PAC can better support meaningful engagement across diverse populations.

Standardisation of PAC

A consistent recommendation throughout the thesis is the need for greater standardisation in the delivery of PAC. While the individualised nature of PAC is one of its strengths, the lack of a consistent framework leads to significant variability in the quality of care provided to people with dementia and their carers. This variability can be owed to the experience and confidence of the healthcare professional delivering PAC, as noted in Chapters 4 and 5, where it is discussed how this can lead to unequal experiences, impacting upon the benefits that people with dementia can gain from this intervention.

Through the standardisation of PAC, people with dementia and their carers would be guaranteed to receive high-quality care irrespective of the healthcare professional conducting the appointment or their geographical location (Prince et al., 2016). This approach would enable healthcare professionals to follow a clear framework where the key components of

PAC, such as clarity of information and communication, empowerment and emotional and psychological support, are provided to a gold standard. However, this thesis also highlights the need for an element of flexibility to accommodate contextual and cultural factors while adhering to the principles of a standardised approach. PAC can thus be made to be culturally appropriate for diverse populations by altering the way it is conducted according to the context of the culture and healthcare systems.

More research is needed in order to create a framework based on empirical best practices for the delivery of PAC and to establish a best practice that can be followed in diverse healthcare services. However, it is imperative that this framework is shaped by the experiences of people living with dementia, those who care for them and healthcare professionals from diverse backgrounds to ensure the true universality of PAC.

Psychological Wellbeing

One of the primary goals of PAC is to improve the well-being of both people with dementia and their carers, and this is a theme that runs continuously throughout this thesis. Chapter 6 demonstrated how PAC has the potential to significantly reduce the stress of people with dementia throughout their dementia diagnosis journey through the provision of clarity and structure during this process. Chapter 5 found that for carers, the emotional support provided through PAC appears to enable readiness for a potential diagnosis and challenges thereafter and supports their psychological well-being.

Despite the positive impact PAC seemingly has upon stress in people with dementia, this thesis has also noted the limitations in improving fear of dementia, depression and anxiety, factors that are highly prevalent within this population (Lueng et al., 2021; Regan & Varanelli, 2013). PAC appears to dissipate some of the stress that people with dementia feel at the beginning of their diagnosis journey, but it may not alleviate some of the more persistent worries and concerns that they and their carers experience. Further interventions such as peer support groups, talking therapies or cognitive behaviour therapy may be required to manage these effectively (Livingston et al., 2013).

Other services that are accessible to people with dementia and their carers may be able to incorporate PAC within their support frameworks. For example, services providing as social support may be able to include some of the fundamental components of PAC that this thesis has uncovered to provide more comprehensive care and holistic support to meet challenges encountered by people living with dementia and those who care for them.

Dementia is a global health crisis and affects millions of people across a multitude of cultural and socioeconomic backgrounds, and the number of people developing the condition is rising (Prince et al., 2014; WHO, 2021). Healthcare systems across the world are attempting to meet this growing challenge, and PAC emerges as a potentially critical tool to empower people with dementia and aid carers by promoting informed decision-making and mitigating psychological distress. Integrating PAC into global dementia management strategies supports early diagnosis and ensures that the emotional and psychological needs of people living with dementia are addressed, as well as those who care for them. To make meaningful progress, PAC should be incorporated into international efforts to improve dementia care, with a particular emphasis on cultural adaptability and equitable access for all communities.

These findings strengthen the case for PAC to be routinely offered to all carers of people with dementia as they provide clear indications that the intervention is not only well received but also has a measurable and positive impact on carers' experiences of care and psychological wellbeing. Although this study included a comparison group of carers who did not receive PAC, the design was not randomised, and group allocation was based on existing service structures rather than experimental assignment. This introduces the possibility of selection bias or unmeasured differences between groups that could have influenced the outcomes. As such, while the findings are promising, they should be interpreted cautiously.

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Appendices

Appendix 1: CASP Checklist For Qualitative Research

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	
3. Was the research design appropriate to address the aims of the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER:	

• *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	☐Yes ☐ No ☐ Can’t Tell
CONSIDER: • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	
5. Was the data collected in a way that addressed the research issue?	☐Yes ☐ No ☐ Can’t Tell
CONSIDER: • *If the setting for the data collection was justified* • *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)* • *If the researcher has justified the methods chosen* • *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)* • *If methods were modified during the study. If so, has the researcher explained how and why* • *If the form of data is clear (e.g. tape recordings, video material, notes etc.)* • *If the researcher has discussed saturation of data*	
6. Has the relationship between researcher and participants been adequately considered?	☐Yes ☐ No ☐ Can’t Tell
CONSIDER: • *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location* • *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*	

Section B: What are the results?

7. Have ethical issues been taken into consideration?

☐ Yes ☐ No ☐ Can’t Tell

CONSIDER:

- *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*
- *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)*
- *If approval has been sought from the ethics committee*

8. Was the data analysis sufficiently rigorous?

☐ Yes ☐ No ☐ Can’t Tell

CONSIDER:

- *If there is an in-depth description of the analysis process*
- *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data*
- *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process*
- *If sufficient data are presented to support the findings*
- *To what extent contradictory data are taken into account*
- *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*

9. Is there a clear statement of findings?

☐ Yes ☐ No ☐ Can’t Tell

CONSIDER:

- *If the findings are explicit*
- *If there is adequate discussion of the evidence both for and against the researcher’s arguments*
- *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)*
- *If the findings are discussed in relation to the original research question*

Section C: Will the results help locally?

10. How valuable is the research?	☐ Yes ☐ No ☐ Can’t Tell

CONSIDER:

- *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature*
- *If they identify new areas where research is necessary*
- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

Positive/Methodologically sound	**Negative/Relatively poor methodology**	**Unknowns**

Appendix 2: The Mixed Methods Appraisal Tool (MMAT)

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				

	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Part II: Explanations

1. Qualitative studies	Methodological quality criteria
“Qualitative research is an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem” (Creswell, 2013b, p. 3). Common qualitative research approaches include (this list if not exhaustive): **Ethnography** The aim of the study is to describe and interpret the shared cultural behaviour of a group of individuals. **Phenomenology** The study focuses on the subjective experiences and interpretations of a phenomenon encountered by individuals. **Narrative research** The study analyzes life experiences of an individual or a group. **Grounded theory** Generation of theory from data in the process of conducting research (data collection occurs first). **Case study** In-depth exploration and/or explanation of issues intrinsic to a particular case. A case can be anything from a decision-making process, to a person, an organization, or a country.	1.1. Is the qualitative approach appropriate to answer the research question? Explanations The qualitative approach used in a study (see non-exhaustive list on the left side of this table) should be appropriate for the research question and problem. For example, the use of a grounded theory approach should address the development of a theory and ethnography should study human cultures and societies. This criterion was considered important to add in the MMAT since there is only one category of criteria for qualitative studies (compared to three for quantitative studies).
	1.2. Are the qualitative data collection methods adequate to address the research question? Explanations This criterion is related to data collection method, including data sources (e.g., archives, documents), used to address the research question. To judge this criterion, consider whether the method of data collection (e.g., in depth interviews and/or group interviews, and/or observations) and the form of the data (e.g., tape recording, video material, diary, photo, and/or field notes) are adequate. Also, clear justifications are needed when data collection methods are modified during the study.
	1.3. Are the findings adequately derived from the data? Explanations This criterion is related to the data analysis used. Several data analysis methods have been developed and their use depends on the research question and qualitative approach. For example, open, axial and selective coding is often associated with grounded theory, and within- and cross-case analysis is often seen in case study.
	1.4. Is the interpretation of results sufficiently substantiated by data? Explanations The interpretation of results should be supported by the data collected. For example, the quotes provided to justify the themes should be adequate.

Qualitative description There is no specific methodology, but a qualitative data collection and analysis, e.g., in-depth interviews or focus groups, and hybrid thematic analysis (inductive and deductive). Key references: Creswell (2013a); Sandelowski (2010); Schwandt (2015)	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? Explanations There should be clear links between data sources, collection, analysis and interpretation.

2. Quantitative randomized controlled trials	**Methodological quality criteria**
Randomized controlled clinical trial: A clinical study in which individual participants are allocated to intervention or control groups by randomization (intervention assigned by researchers). Key references: Higgins and Green (2008); Higgins et al. (2016); Oxford Centre for Evidence-based Medicine (2016); Porta et al. (2014)	2.1. Is randomization appropriately performed? Explanations In a randomized controlled trial, the allocation of a participant (or a data collection unit, e.g., a school) into the intervention or control group is based solely on chance. Researchers should describe how the randomization schedule was generated. A simple statement such as ‘we randomly allocated’ or ‘using a randomized design’ is insufficient to judge if randomization was appropriately performed. Also, assignment that is predictable such as using odd and even record numbers or dates is not appropriate. At minimum, a simple allocation (or unrestricted allocation) should be performed by following a predetermined plan/sequence. It is usually achieved by referring to a published list of random numbers, or to a list of random assignments generated by a computer. Also, restricted allocation can be performed such as blocked randomization (to ensure particular allocation ratios to the intervention groups), stratified randomization (randomization performed separately within strata), or minimization (to make small groups closely similar with respect to several characteristics). Another important characteristic to judge if randomization was appropriately performed is allocation concealment that protects assignment sequence until allocation. Researchers and participants should be unaware of the assignment sequence up to the point of allocation. Several strategies can be used to ensure allocation concealment such relying on a central randomization by a third party, or the use of sequentially numbered, opaque, sealed envelopes (Higgins et al., 2016).
	2.2. Are the groups comparable at baseline? Explanations Baseline imbalance between groups suggests that there are problems with the randomization. Indicators from baseline imbalance include: “(1) unusually large differences between intervention group sizes; (2) a substantial excess in statistically significant differences in baseline characteristics than would be expected by chance alone; (3) imbalance in key prognostic factors (or baseline measures of outcome variables) that are unlikely to be due to chance; (4) excessive similarity in baseline characteristics that is not compatible with chance; (5) surprising absence of one or more key characteristics that would be expected to be reported” (Higgins et al., 2016, p. 10).
	2.3. Are there complete outcome data? Explanations Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field and apply this uniformly across all the included studies. For instance, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for a follow-up of more than one year (Viswanathan and Berkman, 2012).

	2.4. Are outcome assessors blinded to the intervention provided? Explanations Outcome assessors should be unaware of who is receiving which interventions. The assessors can be the participants if using participant reported outcome (e.g., pain), the intervention provider (e.g., clinical exam), or other persons not involved in the intervention (Higgins et al., 2016).
	2.5 Did the participants adhere to the assigned intervention? Explanations To judge this criterion, consider the proportion of participants who continued with their assigned intervention throughout follow-up. “Lack of adherence includes imperfect compliance, cessation of intervention, crossovers to the comparator intervention and switches to another active intervention.” (Higgins et al., 2016, p. 25).

3. Quantitative non-randomized studies	**Methodological quality criteria**
Non-randomized studies are defined as any quantitative studies estimating the effectiveness of an intervention or studying other exposures that do not use randomization to allocate units to comparison groups (Higgins and Green, 2008). Common designs include (this list if not exhaustive): **Non-randomized controlled trials** The intervention is assigned by researchers, but there is no randomization, e.g., a pseudo-randomization. A non-random method of allocation is not reliable in producing alone similar groups. **Cohort study** Subsets of a defined population are assessed as exposed, not exposed, or exposed at different degrees to factors of interest. Participants are followed over time to determine if an outcome occurs (prospective longitudinal). **Case-control study**	3.1. Are the participants representative of the target population? Explanations Indicators of representativeness include: clear description of the target population and of the sample (inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the intervention/exposure and outcome of interest are used, or variables are measured using ‘gold standard’.
	3.3. Are there complete outcome data? Explanations Almost all the participants contributed to almost all measures. There is no absolute and standard cut-off value for acceptable complete outcome data. Agree among your team what is considered complete outcome data in your field (and based on the targeted journal) and apply this uniformly across all the included studies. For example, in the literature, acceptable complete data value ranged from 80% (Thomas et al., 2004; Zaza et al., 2000) to 95% (Higgins et al., 2016). Similarly, different acceptable withdrawal/dropouts rates have been suggested: 5% (de Vet et al., 1997; MacLehose et al., 2000), 20% (Sindhu et al., 1997; Van Tulder et al., 2003) and 30% for follow-up of more than one year (Viswanathan and Berkman, 2012).

Cases, e.g., patients, associated with a certain outcome are selected, alongside a corresponding group of controls. Data is collected on whether cases and controls were exposed to the factor under study (retrospective). **Cross-sectional analytic study** At one particular time, the relationship between health-related characteristics (outcome) and other factors (intervention/exposure) is examined. E.g., the frequency of outcomes is compared in different population subgroups according to the presence/absence (or level) of the intervention/exposure. Key references for non-randomized studies: Higgins and Green (2008); Porta et al. (2014); Sterne et al. (2016); Wells et al. (2000)	3.4. Are the confounders accounted for in the design and analysis? Explanations Confounders are factors that predict both the outcome of interest and the intervention received/exposure at baseline. They can distort the interpretation of findings and need to be considered in the design and analysis of a non-randomized study. Confounding bias is low if there is no confounding expected, or appropriate methods to control for confounders are used (such as stratification, regression, matching, standardization, and inverse probability weighting).
	3.5 During the study period, is the intervention administered (or exposure occurred) as intended? Explanations For intervention studies, consider whether the participants were treated in a way that is consistent with the planned intervention. Since the intervention is assigned by researchers, consider whether there was a presence of contamination (e.g., the control group may be indirectly exposed to the intervention) or whether unplanned co-interventions were present in one group (Sterne et al., 2016). For observational studies, consider whether changes occurred in the exposure status among the participants. If yes, check if these changes are likely to influence the outcome of interest, were adjusted for, or whether unplanned co-exposures were present in one group (Morgan et al., 2017).

4. Quantitative descriptive studies	**Methodological quality criteria**
Quantitative descriptive studies are “concerned with and designed only to describe the existing distribution of variables without much regard to causal relationships or other hypotheses” (Porta et al., 2014, p. 72). They are used to monitoring the population, planning, and generating hypothesis (Grimes and Schulz, 2002). Common designs include the following single-group studies (this list if not exhaustive): **Incidence or prevalence study without comparison group** In a defined population at one particular time, what is	4.1. Is the sampling strategy relevant to address the research question? Explanations Sampling strategy refers to the way the sample was selected. There are two main categories of sampling strategies: probability sampling (involve random selection) and non-probability sampling. Depending on the research question, probability sampling might be preferable. Non-probability sampling does not provide equal chance of being selected. To judge this criterion, consider whether the source of sample is relevant to the target population; a clear justification of the sample frame used is provided; or the sampling procedure is adequate.
	4.2. Is the sample representative of the target population? Explanations There should be a match between respondents and the target population. Indicators of representativeness include: clear description of the target population and of the sample (such as respective sizes and inclusion and exclusion criteria), reasons why certain eligible individuals chose not to participate, and any attempts to achieve a sample of participants that represents the target population.

happening in a population, e.g., frequencies of factors (importance of problems), is described (portrayed). **Survey** “Research method by which information is gathered by asking people questions on a specific topic and the data collection procedure is standardized and well defined.” (Bennett et al., 2011, p. 3). **Case series** A collection of individuals with similar characteristics are used to describe an outcome. **Case report** An individual or a group with a unique/unusual outcome is described in detail. Key references: Critical Appraisal Skills Programme (2017); Draugalis et al. (2008)	4.3. Are the measurements appropriate? Explanations Indicators of appropriate measurements include: the variables are clearly defined and accurately measured, the measurements are justified and appropriate for answering the research question; the measurements reflect what they are supposed to measure; validated and reliability tested measures of the outcome of interest are used, variables are measured using ‘gold standard’, or questionnaires are pre-tested prior to data collection.
	4.4. Is the risk of nonresponse bias low? Explanations Nonresponse bias consists of “an error of nonobservation reflecting an unsuccessful attempt to obtain the desired information from an eligible unit.” (Federal Committee on Statistical Methodology, 2001, p. 6). To judge this criterion, consider whether the respondents and non-respondents are different on the variable of interest. This information might not always be reported in a paper. Some indicators of low nonresponse bias can be considered such as a low nonresponse rate, reasons for nonresponse (e.g., noncontacts vs. refusals), and statistical compensation for nonresponse (e.g., imputation). The nonresponse bias is might not be pertinent for case series and case report. This criterion could be adapted. For instance, complete data on the cases might be important to consider in these designs.
	4.5. Is the statistical analysis appropriate to answer the research question? Explanations The statistical analyses used should be clearly stated and justified in order to judge if they are appropriate for the design and research question, and if any problems with data analysis limited the interpretation of the results.

5. Mixed methods studies	**Methodological quality criteria**
Mixed methods (MM) research involves combining qualitative (QUAL) and quantitative (QUAN) methods. In this tool, to be considered MM, studies have to meet the following criteria (Creswell and Plano Clark, 2017): (a) at least one QUAL method and one QUAN method are combined; (b) each method is used rigorously in accordance to the generally accepted criteria in the area (or tradition) of research invoked; and (c) the combination of the methods is carried out at the minimum through a MM design (defined *a priori*, or emerging) and the integration of the QUAL and QUAN phases, results, and data. Common designs include (this list if not exhaustive): **Convergent design** The QUAL and QUAN components are usually (but not necessarily) concomitant. The purpose is to examine the same phenomenon by interpreting QUAL and QUAN results (bringing data analysis together at the interpretation stage), or by integrating QUAL and QUAN datasets (e.g., data on same cases), or by transforming data (e.g., quantization of qualitative data). **Sequential explanatory design** Results of the phase 1 - QUAN component inform the phase 2 - QUAL component. The purpose is to explain QUAN results using QUAL findings. E.g., the QUAN results guide the selection of QUAL data sources and data collection, and the QUAL findings contribute to the interpretation of QUAN results. **Sequential exploratory design** Results of the phase 1 - QUAL component inform the phase 2 - QUAN component. The purpose is to explore, develop and test an instrument (or taxonomy), or a conceptual framework (or theoretical model). E.g., the QUAL findings inform the QUAN data collection, and the QUAN results allow a statistical generalization of the QUAL findings. Key references: Creswell et al. (2011); Creswell and Plano Clark, (2017); O'Cathain (2010)	5.1. Is there an adequate rationale for using a mixed methods design to address the research question? Explanations The reasons for conducting a mixed methods study should be clearly explained. Several reasons can be invoked such as to enhance or build upon qualitative findings with quantitative results and vice versa; to provide a comprehensive and complete understanding of a phenomenon or to develop and test instruments (Bryman, 2006).
	5.2. Are the different components of the study effectively integrated to answer the research question? Explanations Integration is a core component of mixed methods research and is defined as the "explicit interrelating of the quantitative and qualitative component in a mixed methods study" (Plano Clark and Ivankova, 2015, p. 40). Look for information on how qualitative and quantitative phases, results, and data were integrated (Pluye et al., 2018). For instance, how data gathered by both research methods was brought together to form a complete picture (e.g., joint displays) and when integration occurred (e.g., during the data collection-analysis or/and during the interpretation of qualitative and quantitative results).
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? Explanations This criterion is related to meta-inference, which is defined as the overall interpretations derived from integrating qualitative and quantitative findings (Teddlie and Tashakkori, 2009). Meta-inference occurs during the interpretation of the findings from the integration of the qualitative and quantitative components, and shows the added value of conducting a mixed methods study rather than having two separate studies.
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? Explanations When integrating the findings from the qualitative and quantitative components, divergences and inconsistencies (also called conflicts, contradictions, discordances, discrepancies, and dissonances) can be found. It is not sufficient to only report the divergences; they need to be explained. Different strategies to address the divergences have been suggested such as reconciliation, initiation, bracketing and exclusion (Pluye et al., 2009b). Rate this criterion 'Yes' if there is no divergence.
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? Explanations The quality of the qualitative and quantitative components should be individually appraised to ensure that no important threats to trustworthiness are present. To appraise 5.5, use criteria for the qualitative component (1.1 to 1.5), and the appropriate criteria for the quantitative component (2.1 to 2.5, or 3.1 to 3.5, or 4.1 to 4.5). The quality of both components should be high for the mixed methods study to be considered of good quality. The premise is that the overall quality of a mixed methods study cannot exceed the quality of its weakest component. For example, if the quantitative component is rated high quality and the qualitative component is rated low quality, the overall rating for this criterion will be of low quality.

Appendix 3: The Effective Practice Health Practice Project (EPHPP) for Quantitative Studies

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

1 Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

1 80 - 100% agreement
2 60 – 79% agreement
3 less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
5 Cohort (one group pre + post (before and after))
6 Interrupted time series
7 Other specify ______________________
8 Can't tell

Was the study described as randomized? If NO, go to Component C.

No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1 Yes
2 No
3 Can't tell

The following are examples of confounders:

1 Race
2 Sex
3 Marital status/family
4 Age
5 SES (income or class)
6 Education
7 Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

1 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes
2 No
3 Can't tell

(Q2) Were the study participants aware of the research question?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1 Yes
2 No
3 Can't tell

(Q2) Were data collection tools shown to be reliable?

1 Yes
2 No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1 80 -100%

2 60 - 79%

3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1 80 -100%

2 60 - 79%

3 less than 60%

4 Can’t tell

(Q2) Was the consistency of the intervention measured?

1 Yes
2 No
3 Can’t tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4 Yes
5 No
6 Can’t tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1 Yes
2 No
3 Can’t tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes
2 No
3 Can’t tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	MODERATE	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

Final decision of both reviewers (circle one):	**1**	**STRONG**
	2	**MODERATE**
	3	**WEAK**

Appendix 4: NICE Quality Appraisal Checklist

++	Indicates that for that particular aspect of study design, the study has been designed or conducted in such a way as to minimise the risk of bias.
+	Indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design.
−	Should be reserved for those aspects of the study design in which significant sources of bias may persist.
Not reported (NR)	Should be reserved for those aspects in which the study under review fails to report how they have (or might have) been considered.
Not applicable (NA)	Should be reserved for those study design aspects that are not applicable given the study design under review (for example, allocation concealment would not be applicable for case–control studies).

Appendix 5: Fear of Dementia (FoD) Scale

How concerned or fearful are you about the following aspects related to having Alzheimer's Disease? Please read each item carefully and circle the number that best represents your feeling.

	1 Not at all likely	**2 Rarely likely**	**3 Generally likely**	**4 Often likely**	**5 Very likely**
I am afraid of getting dementia because it would lead to economic woes					
I am afraid of getting dementia because I may be unable to take care of my family					
I am afraid of getting dementia because I may present an economic burden to my family					
I am afraid of getting dementia because I may be a burden to my family					
I am afraid of getting dementia because I may not be able to support my family economically					
I am afraid of getting dementia because I may not be able to carry out my daily activities by myself (e.g., wearing clothes, washing, eating)					
I am afraid of getting dementia because I may do things that I myself do not know of (e.g., doubting, obsessing, wandering, repeated behaviors, etc)					
I am afraid of getting dementia because I may have to depend on others to live					
I am afraid of getting dementia because they say that dementia has no cure					
I am afraid of getting dementia because my conditions worsen as time passes					
I am afraid of getting dementia treatments do not work on dementia					
When I look at family, neighbors and other who have dementia, I am afraid I may be like them					

I lose sleep if I think about myself getting dementia					
My heartbeat increases if I think of myself getting dementia					
My hands sweat if I think of myself getting dementia					
I lose my appetite if I think of myself getting dementia					
I am afraid of getting dementia because those around me would think I am mentally challenged					
I am afraid of getting dementia as I may lose face					
I am afraid of people knowing that I have dementia					
I am afraid of getting dementia because my family and friends will avoid me					
I am afraid if I may have contracted dementia as my cognitive abilities have decreased as of recent (e.g., losing things often, forgetting what I had just said, I cannot remember what I want to say, etc.)					
I am afraid if I may have contracted dementia as my memory has been poor as of recent.					
I will be anxious if I have dementia					
Even if my memory is normal right now, I am afraid that I may get dementia in the future					
I become more afraid of contracting dementia as I get older					
I am afraid of dementia because with age, everyone seems to get it					
I am afraid of dementia because I may not be able to engage in social activities (e.g. class reunions, hobby groups)					
I am afraid of getting dementia because I may not be able to recognise my family and friends					
I am afraid of getting dementia as I will be alone					

Appendix 6: Depression, Anxiety and Stress Scale (DASS-21)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0	Did not apply to me at all
1	Applied to me to some degree, or some of the time
2	Applied to me to a considerable degree or a good part of time
3	Applied to me very much or most of the time

I found it hard to wind down	0	1	2	3
I was aware of dryness of my mouth	0	1	2	3
I couldn’t seem to experience any positive feeling at all	0	1	2	3
I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
I found it difficult to work up the initiative to do things	0	1	2	3
I tended to over-react to situations	0	1	2	3
I experienced trembling (e.g. in the hands)	0	1	2	3
I felt that I was using a lot of nervous energy	0	1	2	3
I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
I felt that I had nothing to look forward to	0	1	2	3
I found myself getting agitated	0	1	2	3
I found it difficult to relax	0	1	2	3
I felt down-hearted and blue	0	1	2	3
I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
I felt I was close to panic	0	1	2	3
I was unable to become enthusiastic about anything	0	1	2	3
I felt I wasn’t worth much as a person	0	1	2	3
I felt that I was rather touchy	0	1	2	3
I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
I felt scared without any good reason	0	1	2	3
I felt that life was meaningless	0	1	2	3

Depression, Anxiety and Stress scale (Gomez, 2016) **Version to be used after PAC session**

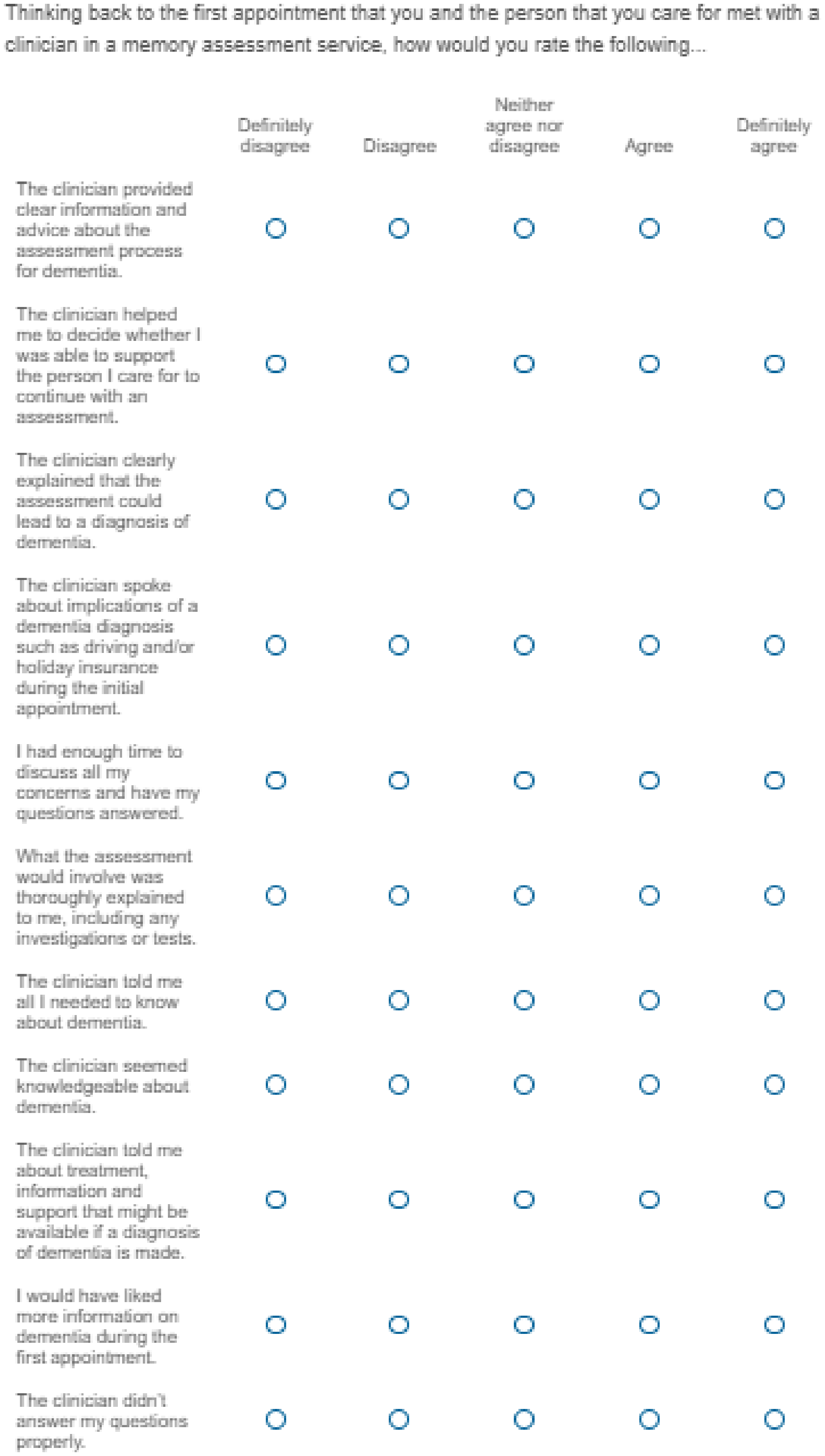
Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the coming week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0	Will not apply to me at all
1	Will apply to me to some degree, or some of the time
2	Will apply to me to a considerable degree or a good part of time
3	Will apply to me very much or most of the time

I will find it hard to wind down	0	1	2	3
I will be aware of dryness of my mouth	0	1	2	3
I will not seem to experience any positive feeling at all	0	1	2	3
I will experience breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
I will find it difficult to work up the initiative to do things	0	1	2	3
I will tend to over-react to situations	0	1	2	3
I will experience trembling (e.g. in the hands)	0	1	2	3
I will feel that I will use a lot of nervous energy	0	1	2	3
I will worry about situations in which I might panic and make a fool of myself	0	1	2	3
I will feel that I have nothing to look forward to	0	1	2	3
I will find myself getting agitated	0	1	2	3
I will find it difficult to relax	0	1	2	3
I will feel down-hearted and blue	0	1	2	3
I will be intolerant of anything that keeps me from getting on with what I am doing	0	1	2	3
I will feel that I am close to panic	0	1	2	3
I will be unable to become enthusiastic about anything	0	1	2	3
I will feel I am not worth much as a person	0	1	2	3
I will feel that I am rather touchy	0	1	2	3
I will be aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
I will feel scared without any good reason	0	1	2	3
I will feel that life is meaningless	0	1	2	3

Appendix 7: Initial Appointment Experience Scale



Thinking back to the first appointment that you and the person that you care for met with a clinician in a memory assessment service, how would you rate the following...

	Definitely disagree	Disagree	Neither agree nor disagree	Agree	Definitely agree
The clinician provided clear information and advice about the assessment process for dementia.	○	○	○	○	○
The clinician helped me to decide whether I was able to support the person I care for to continue with an assessment.	○	○	○	○	○
The clinician clearly explained that the assessment could lead to a diagnosis of dementia.	○	○	○	○	○
The clinician spoke about implications of a dementia diagnosis such as driving and/or holiday insurance during the initial appointment.	○	○	○	○	○
I had enough time to discuss all my concerns and have my questions answered.	○	○	○	○	○
What the assessment would involve was thoroughly explained to me, including any investigations or tests.	○	○	○	○	○
The clinician told me all I needed to know about dementia.	○	○	○	○	○
The clinician seemed knowledgeable about dementia.	○	○	○	○	○
The clinician told me about treatment, information and support that might be available if a diagnosis of dementia is made.	○	○	○	○	○
I would have liked more information on dementia during the first appointment.	○	○	○	○	○
The clinician didn't answer my questions properly.	○	○	○	○	○

Thinking back to the first appointment that you and the person that you care for met with a clinician in a memory assessment service, how would you rate the following...

	Definitely disagree	Disagree	Neither agree nor disagree	Agree	Definitely agree
I felt at ease after speaking with the clinician.	○	○	○	○	○
Dementia, and what it meant to me and what it meant to the person that I care for, was discussed in the initial conversation with the clinician.	○	○	○	○	○
The clinician talked about some of the possible benefits of having a confirmed diagnosis of dementia.	○	○	○	○	○
The clinician asked about my wellbeing as a carer for someone who might have dementia.	○	○	○	○	○
I felt as though I could make choices about the person I support.	○	○	○	○	○
I was involved in the decisions about the assessment process.	○	○	○	○	○

Thinking back to the first appointment that you and the person that you care for met with a clinician in a memory assessment service, how would you rate the following...

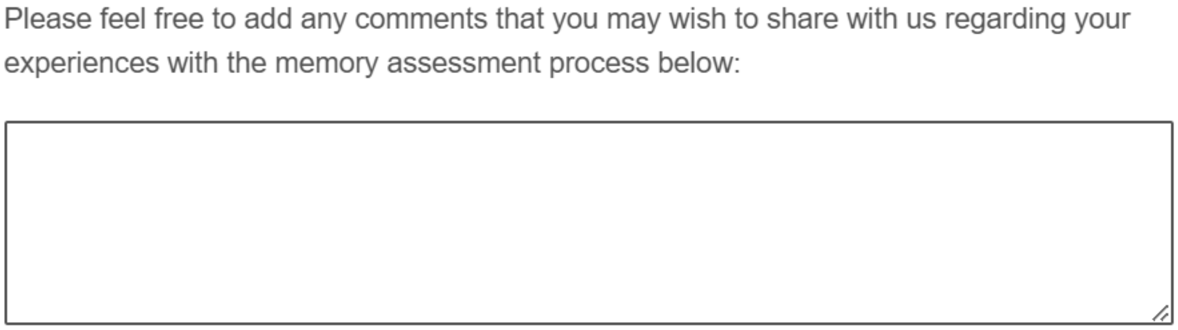
	Definitely disagree	Disagree	Agree nor disagree	Agree	Definitely agree
I felt understood by the clinician.	○	○	○	○	○
The clinician made me feel that what I said was important.	○	○	○	○	○
The clinician took my concerns seriously.	○	○	○	○	○
I felt able to freely to talk about my concerns with the clinician.	○	○	○	○	○
I felt able to ask the clinician questions.	○	○	○	○	○
The clinician answered my questions honestly.	○	○	○	○	○

Appendix 8: The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)

Over the last 2 weeks, how would you rate yourself on the following statements?

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future.	○	○	○	○	○
I've been feeling useful.	○	○	○	○	○
I've been feeling relaxed.	○	○	○	○	○
I've been feeling interested in other people.	○	○	○	○	○
I've had energy to spare.	○	○	○	○	○
I've been dealing with problems well.	○	○	○	○	○
I've been thinking clearly.	○	○	○	○	○
I've been feeling good about myself.	○	○	○	○	○
I've been feeling close to other people.	○	○	○	○	○
I've been feeling confident.	○	○	○	○	○
I've been able to make up my own mind about things.	○	○	○	○	○
I've been feeling loved.	○	○	○	○	○

	None of the time	Rarely	Some of the time	Often	All of the time
I've been interested in new things.	○	○	○	○	○
I've been feeling cheerful.	○	○	○	○	○



Please feel free to add any comments that you may wish to share with us regarding your experiences with the memory assessment process below: