Illness Perceptions and Help - Seeking Intentions Among People with Early-Stage Dementia and Their Caregivers

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This thesis is submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy. The candidate has already achieved 180 credits for assessment of taught modules within the blended learning PhD programme.

Month and Year of submission

May 2023

Faculty of Health and Medicine

Lancaster University

I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Abstract

Objectives: The majority of people with mild to moderate dementia in the United Kingdom (UK) are cared for by informal caregivers (CGs), usually spouses and close family members. However, surprisingly little is known about the influence of the dyadic relationship in regard to an individual's own help-seeking once receiving a diagnosis of dementia. Using the conceptual framework of the Self-Regulatory Model (SRM), the aim of this study was to examine the illness perceptions of people with early-stage dementia and their CG in relation to their own help- seeking. Also, the effect of the relationship between both members of the dyad on their own illness perceptions with their own help-seeking intentions was examined.

Methods: A cross-sectional study of 56 dyads (person with dementia and CG) applied the five dimensions of the Illness Perception Questionnaire (IPQ-R) to assess illness perceptions of dementia and the General Help Seeking Questionnaire (GHSQ) to measure help-seeking. Dyads were recruited from 9 community mental health teams for older adults from an NHS trust in the UK.

Findings: To answer the research question a systematic literature review of 14 studies revealed that an individual's illness perceptions of dementia were related to their own cultural beliefs, acceptance, stigma, and experiences of dementia services, and that these perceptions influenced their own help-seeking intentions. In response to the literature review, an Actor Partner Independence Model (APIM) analysis of the person with dementia and their carers illness perceptions revealed a significant actor effect for identity with help-seeking for the person with dementia and for physical and behaviour cause with help-seeking for the CG. However, there were no partner effects across dyads, both between and within the person with dementia and the CG.

Conclusion: This is the first study to utilise the IPQ-R with people living with dementia. Examining illness perceptions with help-seeking, the modified IPQ-R showed inconsistencies regarding validity and reliability for the IPQ-R subscales of control, consequences, coherence, and timeline acute. Thus,

suggestions are made to consider adaptations to the IPQ-R regarding language used for people living with dementia.

The observation of illness perceptions and help-seeking within the dyadic relationship revealed a lack of partner effects, suggesting that an individual's own perceptions of dementia did not have an impact on their partners help-seeking. This suggests that members of the dyad are not connecting with each other about their perceptions of living with dementia and may result in delayed help-seeking. Thus, future interventions focussing on a more shared understanding of illness perceptions between both members of the dyad may help identify what support is needed for people living with dementia as they learn to live with the illness, thus improving their quality of life.

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Acknowledgments

Firstly, I would like to extend my gratitude and thanks to all of the patients and their caregivers who took part in this study; without them this piece of research would not have been possible. I would also like to pay thanks to the NHS mental health care staff who kindly let me access their clinics and community services to help with the promotion and recruitment of participants for this study.

I would also like to thank my supervisors Dr Guillermo Perez Algorta and Professor Jane Simpson. As I have balanced a busy work life in NHS management with the academic demands of this PhD, their wisdom, patience, and responsiveness have been invaluable in getting me past the final hurdle.

A thankyou is also extended to Professor Ramin Nilforooshan who has supported me through this process, with his expertise in the field of dementia. Also, for being flexible with my change of working patterns to accommodate completion of this Thesis.

Finally, I would like to extend my thanks to family and friends. Andrew for taking time to listen to me when times were tough with his humorous texts and referring to me as Dr Gregg from day one. Also, a special thankyou to my great friend Maggie for her underlying support, who was always so encouraging and supportive and always there when needed. Sadly, Maggie is no longer here to see me achieve this milestone in my life, but I know she will be watching from the side-lines.

This Thesis is dedicated to my Mum “Smiler” You always had a smile on your face and taught me to never give up, no matter what. Your dementia finally took your smile away, but your determination inspired me to keep going to the end.

“The privilege of a lifetime is to become who you truly are”.

Carl Jung 1875-1961

Chapter 1: Background Information

Around the globe people are living longer thus, the proportion of older people worldwide are set to rise (Brayne & Miller, 2017). While this could be seen as a positive development due to advances in medical practice and improved healthcare, it also means that more people will be affected by illnesses associated with old age. Dementia is closely associated with old age, and it is well known that the prevalence of dementia increases with age (Brayne & Wu, 2022). In response to this major health problem, there has been a push both for a timelier diagnosis for dementia and an improvement in the services for people living with dementia (Prince et al.,2016).

No cure for dementia currently exists but an early diagnosis can be beneficial in improving the quality of life for those living with the illness. The World Health Organization (WHO) global action plan on the public health response to dementia (2017-2025) aims to improve the lives of people with dementia and their caregivers (CG). Its main purpose is for people who are living with dementia to live well and to receive the care and support they need so as to fulfil their own potential with respect, dignity, equality, and autonomy. However only one quarter of countries have a national strategy to address this goal (WHO, 2017-2025). Moreover, the WHO (2017-2025) global action plan recommends that after people receive a diagnosis, primary healthcare clinicians should be involved at the beginning of the care plans for individuals, as by being involved from the outset could lead to a decrease in future hospital costs.

In the UK, the report of the All-Party Parliamentary Group on Dementia (APPG, 2014) recommends that people living with dementia have the most to gain from the integrated care they receive via the health and social care sectors. Furthermore, the APPG report argues that people with dementia and their CGs should be involved from the outset in any decisions affecting their care. With regard to these recommendations, the support people receive “at diagnosis and post diagnosis is in need of urgent attention” (APPG report 2014 p.4). The APPG also suggests that high quality care, information and advice given post diagnosis can aid the person with dementia and their carer to understand the illness, helping individuals enjoy a better quality of life, and plan for the future while still able to do so. Considering the significant psychological and physical changes that can occur with dementia, such as memory problems, communication and language difficulties, people with dementia have reported a lower quality of life compared to the general population of people over 65 (Clare et al., 2014).

Given the complexity of providing support for people living with dementia and the variations in symptoms they experience as well as the individual experiences of people affected by the disease, the United Kingdom (UK) National Institute for Care and Excellence (NICE, 2018) has recommended a person-centred care approach. The principles of this approach emphasise the importance of the individuality of people living with dementia and how their own life experiences and personality influence their response to a diagnosis of dementia. It also highlights the importance of the individual's perspective, interactions with others and the needs of CGs. Encouraging people living with dementia to be involved in decisions about their care enables them to express their own views and opinions and gives them access to relevant information that can be associated with their own individual circumstances (NICE, 2018).

Seeking help once diagnosed with dementia has shown to increase knowledge of dementia (i.e., of symptoms and treatment control) and the perceived benefits of post diagnostic interventions (Devoy & Simpson, 2016). Generally, the illness perceptions of an individual's own health beliefs have proved to be an important determinant of behaviour and have been related to health outcomes such as adherence to treatment and functional recovery (Petrie, et al., 2007). A better understanding of an individual's illness perceptions of dementia and their own help-seeking can serve to improve dementia services for both the person with dementia and their CG.

My interest in the topic of help-seeking for dementia and the association with a person's own illness perceptions (health beliefs) stems from my experience of caring for a parent with dementia and my professional role as an NHS researcher working with people with dementia and their CGs. The experience of working with people living with dementia resonated with my own experiences, and what struck me was that after receiving a diagnosis, so many people struggled with knowing where to turn to for support. From my own positional perspective my methodological choices considered my own assumptions and beliefs. Therefore, by adopting a positivist paradigm, I aimed to conduct this piece of research from an objective stance, thus aiming to maintain impartiality and reducing any personal biases. By taking this approach my aim is to maintain integrity within the research processes applied to this study.

What also interested me was how people differed in their perceptions of dementia and how the relationship between the person with dementia and their CG led to their own specific care plan trajectories. For example, the person with dementia may not perceive their dementia as a serious illness but more as part of the ageing process whereas their CG may have different perceptions of the illness. These differing perceptions could have an impact on the help-seeking behaviour of both the person with dementia and the CG. This led me to think about the determinants of an individual's help-seeking intentions and how this is related to their own perceptions of dementia.

Therefore, the core aim of this thesis is to examine the relationship between the illness perceptions of the person with dementia and the CG with their own help-seeking intentions once diagnosed with dementia, and how the influence of the dyadic relationship can impact on an individual's decision to seek help.

Definitions & Key Concepts

Dementia

Dementia is a progressive and chronic condition and one of the greatest health threats facing society today. Dementia is an umbrella term that is used to describe several brain disorders that are associated with symptoms such as loss of memory and psychological changes (Ballard et al., 2011). There are various types of dementia, with Alzheimer’s disease being the most prevalent and accounting for between 60 and 70 % of cases, vascular dementia being the second most common cause of dementia, with 25% of cases, Lewy Body the third most common, affecting around 15% of cases and Frontal-temporal dementia accounting for 5 to 10% of cases (World Health Organization (WHO) retrieved 21st August 2022 from https://www.who.int/news-room/fact-sheets/detail/dementia).

Several different pathological processes are involved in the different types of dementia, although social science research has always maintained that the level of cognitive impairment is equally affected by social factors and societal responses (Kitwood, 1997). Dementia symptoms can present in varying degrees of severity; however, it is generally understood that three stages of the condition will manifest within the individual (Brayne & Wu, 2022). The three stages are: early (mild), middle (moderate) and late (severe): in the early-stage, people may become confused and forgetful and be unable to make simple decisions; in the middle stage, these symptoms can be more marked with the person needing constant reminders; and in the late stage, the individual will become dependent on others and will likely require 24-hour care (Hamilton-West et al., 2010).

Typically, most people will receive their diagnosis at the early stages of the disease (Alzheimer’s Society, 2022). Most pertinently, receiving a diagnosis early in the mild stage of the illness can provide opportunities to implement changes that might have the most impact on the quality of life of the person with dementia and their caregiver. However, it is important to note that dementia is a syndrome, not a disease, and that the clinical symptoms that are seen together to make up the diagnostic picture, are also affected by other factors. For example, cognitive performance is affected by education and the ability to live independently is affected by social factors and physical conditions (Fox, 2013). Given the current incurable status of dementia, it is important to note that a diagnosis in the early stages of the disease is not always sought due to fear and the stigma associated with dementia. Thus, healthcare professionals need to see the value in specific interventions, as raising expectations that may not be effective may cause further distress for the person with dementia and their CG (Fox, 2013).

Globally it is estimated that around 46.8 million people have dementia, a number that is set to double every 20 years to an estimated figure of 131.5 million by 2050 (Parker et al., 2020). Current estimates for the UK report that 900,000 people are living with dementia, and that 700,000 people are classed as informal carers of an individual with dementia (Alzheimer's Society, 2022). By 2040 it is projected that nearly 2 million people in the UK will have a diagnosis of dementia and 1.7 million people will be caregivers of someone with dementia (Alzheimer's Research, 2016). Furthermore, the current cost to the UK economy of dementia care is more than £34.7 billion a year, this being projected to rise to £94.1 billion by 2040. These costs are made up of NHS costs, social care costs and unpaid care costs. The unpaid cost of CGs to those with dementia equates to £13.9 billion a year; this is set to rise to £35.7 billion by 2040 (Wittenberg et al., 2019).

Being a Caregiver

The term “carer” or “caregiver” is used across many areas (e.g., health and social care, research, and government bodies) and is normally used to describe family or informal (unpaid) care-giving roles (Molyneaux et al., 2011). Moreover, Molyneaux et al. (2011) argues that most spouses who find themselves in this situation report that they have always cared for each other within the reciprocal nature of their relationship and thus do not define themselves within this specific “role”. However, for the purposes of this study, the term “caregiver” (CG) will relate to the main significant (informal) person who is currently responsible for the everyday needs of the person with dementia.

A significant amount of research has focused on family caregiving, however, what constitutes ‘caregiving’ is not always clear. Conceptually, there is a general understanding that a family CG is someone who provides support and daily living tasks as unpaid care to a family member or adult friend who is chronically ill, disabled, frail or elderly (Molyneaux et al., 2011). Once an individual positions themselves as a CG, they take on new responsibilities by developing a new framework to form their own self-care strategies. For example, caring for someone with dementia is considered to be one of the most stressful “carer” roles, as the loss of the relationship with their loved one, along with their loved one’s cognitive and behavioural decline, can cause significant carer strain. ‘O’Connor (2007) suggests that by adopting the notion of caring as a “position” rather than a role, the CG of the person with dementia reconsiders the role by denying the loss of their relationship, thus allowing them to cope with the demands they face.

Despite the CG for a person with dementia providing high levels of assistance with personal care and daily living tasks, their use of support services is low, even though with national strategies in place for dementia care (Stephan et al., 2018). To ensure that CGs utilise the support services available, and to minimise burden, the supply and demand for CGs’ service needs must be suitable. Understanding the facilitators and barriers regarding a CG’s help-seeking intentions can be an initial step in helping to determine the delivery of CG support services within the community (Novias et al., 2017).

Caring for a relative with dementia can be an all-consuming task and CGs may devote many hours, usually over a period of years, to the care of their loved one. Research has shown that caring for someone with dementia is associated with increased psychological difficulties including increased levels of anxiety and depression (Joling et al., 2010; Mahoney et al., 2005; & Russo et al., 1995). Moreover, a systematic review by Watson et al. (2019) revealed that the relationship type and quality were important factors associated with depression. For example, adult-child CGs were more at risk of depression than spousal CGs.

Particular behaviours (e.g., delusions, hallucinations) that can occur in the later stages of dementia can be particularly distressing, due to the effect this has on the CG's relationship with the person with dementia, plus providing daily care tasks associated with personal care (Cheng, 2017). Moreover, 95% of people with dementia experience symptoms of depression and apathy (Arvanitakis, et al., 2019), adding to the strain of caring for someone with dementia (Stephan et al., 2018). Within the context of caring for someone who is ill, CG strain is often described as a burden. Higher levels of CG burden are correlated with adverse physical, social, psychological, and financial health outcomes (Shim et al., 2012). However, some CGs of people with dementia have found great joy, satisfaction, and gratitude in their newfound role. How a CG adapts to their role has been shown to be related to their perceptions of the quality of their present and past relationship with their loved one (Kamer, 1997). Also, by having the ability to accept the changes brought about by being a CG, they are able to find meaning within the changes they face (Shim et al., 2012).

Benefits of Early Help Seeking for People living with Dementia

Help seeking can be defined as the communication of a request for assistance, support or advice with help-seeking intentions seen as conscious plans to perform this specific behaviour; these requests for assistance can be from healthcare professionals, family, and friends (White et al., 2018). The stages of help seeking while living with dementia can be identified as illness experience, symptom attribution, decision to seek help and contact with health services (Levkoff et al., 1999).

By seeking help early, the CG of a person with dementia would be less prone to experiencing problems when providing daily care (Commissaris, 1995). Thus, people who have more knowledge of dementia, and what the future may hold for them are better equipped to cope with the daily issues associated with caring for someone with dementia (Chenoweth & Spencer, 1986). Moreover, accessing support early on (i.e., support with personal care and befriending services) may help delay institutionalisation of the person with dementia (Betts-Adam, 2006). Recent studies by Hailstone (2017) and Gielbel et al. (2017) have reported similar findings regarding the issue of social cultural attitudes and a lack of knowledge about dementia, resulting in delayed help-seeking among South Asian communities in London and Greater Manchester.

Chrisp et al. (2012) have proposed that different types of health-related circumstances (i.e., physical dependence, psychological issues) exist where the autonomy of the individual to seek help for themselves is bound by the actions of others. In these situations, the decision to ask for help from the healthcare system may be resisted by both the person with dementia and the CG. Thus, in the case of people living with dementia, it is important to consider decisions such as seeking help from health professionals in the local community are socially prescribed as to encourage a more person - centred approach. Moreover, help seeking during the early stages of dementia can help minimise the impact of caring for someone with dementia on the CGs health (Hossien, 2017).

While several factors may influence help-seeking, recognition or identity can play a major role in the process (Pico et al, 2018). Being able to identify the signs and symptoms of dementia is linked to early help seeking, thus reducing the distress of the illness for the person with dementia and their CG (Perry et al., 2014). Moreover, a study by Keady and Nolan (2003) identified that people with early-stage dementia may recognise changes in themselves but conceal these symptoms from those who care for them, in an attempt to maintain a sense of self in the face of the challenges they are experiencing (Clare, 2003). If the person with dementia and their CG fail to communicate about the changes that they are experiencing after receiving a diagnosis of dementia, there could be a significant delay in seeking help from health professionals. Thus, more positive perceptions of having a diagnosis of dementia can contribute to more positive help-seeking intentions (Phillipson et al., 2015).

The Dyadic Relationship

To understand the complex process of help seeking, it is important to pay attention to the dyadic process between the CG and the person with dementia. Living with and caregiving for someone with dementia is inherently a dyadic process (Moon & Adams, 2012) and a CG's experiences can interrelate with those of the person with dementia (Harris & Titler, 2021). In the dyadic process, the relationship between two individuals can influence health outcomes due to shared common lifestyles and making a health behaviour change is closely linked to couples (Berli et al., 2018). For instance, behavioural symptoms associated with dementia, such as hallucinations and delusional behaviour, can affect the strain associated with being a CG, thus, caregiving coping strategies can have an effect on the CG's feelings of competency and mood (De Vugt et al., 2004).

Favre and Sornette (2015) have proposed a generic model of dyadic social relationships. The model assumes that dyadic interactions affect each individual in three possible ways; each individual can do the same thing as the other individual, a different thing or nothing at all. These social actions can either have a negative or positive effect on the CG receiver's welfare. For example, the perceptions of the person with dementia of their memory problems could be different from that of their CG, thus, affecting decisions to ask for help for both members of the dyad. Kenny et al. (2006) describes the dyad as being the most fundamental component of interpersonal interactions and interpersonal relations.

A systematic review by Braun et al. (2009) explored the dyadic perspective of dementia caregiving in spousal relationships. Conclusions drawn from this review revealed that the dyadic relationship can lead to a better understanding of CG strain, aiding the development of more effective interventions. The reason for this was that spousal CGs reported more compassion and empathy than adult child CGs. However, compared to adult child CGs spousal CGs had a more heightened level of care, and were more prone to developing higher stress levels, physical and health problems, and role overload. Moreover, the review by Braun et al. (2009) identified that studies looking at the dyadic perspective of people living with dementia have mostly focused on the CG’s experiences but that little is known about how the person with dementia and the CG variables interact. The authors report that the perceptions of the person with dementia can be neglected, with clinicians making healthcare plans with little insight into the needs or values of the person with dementia. If the CG does not acknowledge the values of the person with dementia, this may impact on their self-confidence, sense of control or sense of self (Clare, 2003). This can result in CGs making assumptions about the care needs of the person with dementia and disregarding their capabilities and preferences. Doing this can lead to misunderstandings within the dyadic relationship, and cause stress to both parties, with the CG’s coping strategies influencing the person with dementia’s help-seeking behaviour (Whitlatch et al., 2006). Therefore, it is important for CGs to be aware of the care values of the person with dementia (i.e., avoiding being a burden, importance of autonomy) as the relationship between the person with dementia and CG plays an important role in affecting care planning (Miller et al., 2019).

Due to the significant impairments (e.g., cognitive, and social) that are associated with the progressive nature of dementia, the relationship between the CG and the person with dementia can be negatively impacted. Consequently, research has shown caring for someone with dementia can have major consequences on the CG’s health and quality of life (Braun et al., 2009). However, perceptions of the person with dementia can be overlooked as CGs can make important care decisions daily without always understanding the needs of their loved one (Moon et al., 2017).

Predicting Health Behaviour

In Western culture, the rationale behind the study of health behaviours is based on the assumption that mortality risks are largely due to particular behavioural patterns and that these patterns can be modified. The study of health behaviour and outcomes, such as help seeking, is based on two assumptions: firstly, the assumption is that individuals can make positive contributions to their own health and well-being (e.g., healthy eating, exercise); and secondly, the assumption is that negative health behaviours such as smoking and alcohol consumption can be avoided (Connor & Norman, 2005). An overriding theme is that these behaviours can have an immediate and long-term effect and are within an individual's control (Abraham et al., 1998).

The main focus of interest of researchers working on health behaviour outcomes has been the examination of intrinsic factors that can determine specific behaviours (e.g., cognitions, social support, sociodemographic factors, and personality). Among these intrinsic factors, cognitive factors have been identified as the most important determinant of individual health behaviour (Rutter & Rutter, 2002). Models that focus on how cognitive factors produce various social behaviours are usually referred to as social cognition models (SCMs) and have been widely used by researchers in the field of health psychology (e.g., Ogden, 2003). The rationale for focusing on cognitive determinants is that they are considered important causes of health behaviour as they are assumed to be more open to change than other factors such as personality (Connor and Norman, 2005). Thus, interventions that involve manipulation of cognitive factors have been shown to determine/alter health behaviours (Marteau, 1989).

The majority of research into SCMs can be divided into how people make sense of themselves (self-regulation) and others (person perception), with its main focus being on how an individual makes sense of their own social situation (Connor & Norman, 2005). The focus of self-regulation plays an important role in behavioural processes, as an individual may revise or alter their environment so as to create specific outcomes that are in line with their own self-perceptions (Fiske and Taylor, 1991). This behaviour of the individual focuses on the thought processes that can intervene between observed stimuli and an individual's social environment. Social factors (e.g., peer and parental influences) and cultural factors seem to be influential in determining health behaviours, with emotional factors playing an important role in the practice of certain health habits. Cognitive factors, such as awareness and perception of risk factors, perceptions of disease threat, knowledge of the illness and control over performance of the behaviour, have all been identified as variables that determine whether an individual practises good or bad health behaviours (Conner & Norman, 2005).

As previously mentioned, the prevalence of dementia is set to rise, and thus the number of CGs will rise. For this reason, it is important to examine the illness perceptions of CGs for someone with dementia. Examining a CG's illness perceptions of dementia regarding the person they care for and how these causes them to seek support for themselves is important for future care interventions, as this can affect their coping strategies within the context of their own help-seeking intentions (Bassi et al., 2014). In consideration of Bassi's et al. model, it is proposed that Leventhal's et al. (1980) self-regulatory model (SRM) is further developed by examining how a CG's own illness perceptions of dementia has an effect on their own help-seeking behaviour.

As CG's engage in caregiving activities, they begin to form their own illness perceptions about what dementia means to them. Thus, their own cognitive representations of caring for someone with dementia can fluctuate over time and may or may not resonate with those of the person with dementia (Lingler et al., 2016). Understanding how a person with dementia and their CG as a dyad perceives a diagnosis of dementia and the impact on help seeking is important as their own separate illness perceptions may influence their decision to seek help (Chrisp et al., 2012). The dyadic concept considers the person with dementia and CG outcomes (help-seeking intentions) simultaneously, rather than taking the view that help-seeking is an independent and individual process within the dyadic relationship (Miller et al.,2019).

Illness Perceptions

Illness perceptions fall under the category of SCM attribution models where they seek to examine an individual's response to an illness or illness threat. Social cognitive theory (Bandura, 1982) forms the basis of this model and helps determine the nature of an individual's health behaviour. Bandura's approach considers human motivation and the subsequent actions of the individual within the context of specific outcomes and self-efficacy (Bandura, 1982). This approach is consistent with

Leventhal’s self-regulatory model (SRM) (Leventhal, 1984). The SRM builds on Bandura’s approach by describing the mechanisms of predictive behaviours such as self-efficacy (Leventhal et al., 2016). The SRM model represents a dynamic approach of illness perceptions and consists of three stages: firstly, the individual forms an illness representation; secondly, the individual uses these illness representations to guide their own behaviour; and finally, the individual appraises their own health outcomes.

Where these Illness perceptions can be described as an individual’s organised belief patterns about their condition, these perceptions have been found to be key determinants of a person’s behaviour when managing their illness. Thus, individuals build a mental model when faced with a new health threat and this in turn determines how they respond (, Moss- Morris et al., 2002; Petrie & Weinman 1997). These models are based on an individual’s own personal experiences and medical knowledge, and thus guide a person’s coping strategies to help reduce symptoms and manage the emotional response to the health threat (Petrie & Weinman, 2006).

Within the three stages of the SRM, the individual’s illness perceptions fall into five dimensions: identity, timeline, cause, control, and consequences. In general, the identity component reflects the illness label and the perceived symptoms associated with the illness; however, it is not an evaluation of the self within a broader sense (non-illness) (Petrie et al., 2007). The timeline dimension refers to an individual’s perception of the relative chronicity of the illness. Personal control is related to the amount of control an individual has over their illness, and reflects an internal locus of control, which is an individual’s own perception of their illness. Treatment control reflects more a belief in the influence of external factors, such as fate or others’ perceptions (Machado et al., 2019). An individual’s attribution of the cause of an illness contributes to the cause dimension, while perceptions of the potential seriousness of the illness, and its impact on the individual’s well-being makes up the consequences dimension.

A revised version of the constructs of the SRM was developed by Moss-Morris et al. (2002). They argued that the identity dimension did not reflect an individual's understanding of the illness and thus the illness coherence dimension was added. Additionally, emotional representations were included in the revised version. Emotional representations can be described as an individual's negative emotions generated by having the illness (Moss – Morris et al., 2002). Leventhal et al. (1984) proposed that individuals form parallel cognitive and emotional representations when faced with a health threat. These emotional representations provide an explanation for related coping procedures associated with outcomes that are related to emotional issues (Hagger & Orbell,2005).

A meta-analysis by Hagger and Orbell (2003) lends support to the concept of studies employing the SRM. This analysis reviewed 45 studies that examined illness representations in individuals with various physical health conditions and reported that illness perceptions were related to levels of psychological distress and problem-focused coping strategies. Thus, by measuring illness perceptions within specific individuals, the model suggests that new information from the initial stages of the disease can be incorporated into the initial representation of the illness, and that illness perceptions can be a dynamic process.

Assessment of Illness Perceptions

Typically, illness perceptions of people living with dementia are not discussed in clinical settings. However, by not exploring an individual's own perception of their illness can produce a misunderstanding of their present situation. By using a more structured approach, applying self-report measures can provide a self-description in a more reliable manner, as it involves an individual's own self-knowledge, and involves them formulating their own perceptions, as opposed to being influenced by family members or friends (Osberg,1989).

A more formal evaluation, the Illness Perception Questionnaire (IPQ), was devised by Weinman and Petrie (1996) to address this concept. The IPQ's roots are based on the theoretical framework of the SRM (Leventhal et al., 1980); it has been widely used with other mental health conditions such as schizophrenia (Lobban et al., 2005) and enables illness perceptions to be measured quantitively based on self-reports (Pedley et al., 2019). Moss-Morris et al. (2002) amended the original questionnaire and formed the Revised Illness Perception Questionnaire (IPQ-R). The revised version arose from the need to address psychometric issues; additional subscales assessing cyclical timeline perceptions, illness coherence and emotional representations were added. After these revisions, most modified versions of the IPQ-R focus on small adaptions, such as replacing the illness label with "my condition" or disease-specific additions to the more standard identity and cause subscales (Taylor et al., 2017). In support of these adaptions to the IPQ-R, there have been many validated modified versions for patients. For example, the IPQ-R has been modified for patients recovering from myocardial infarction (Brink et al., 2010), and for those experiencing musculoskeletal pain (Leysen et al., 2015) and for cancer patients (Moon et al., 2017).

Broadbent et al. (2006) developed a shorter version of the IPQ-R, the Brief IPQ (BIPQ). The BIPQ has a single scale comprised of nine items summarising the items contained in each subscale of the IPQ-R; its main advantage is its speed of use. However, the IPQ-R offers a more in-depth analysis of the individual's beliefs related to the specific symptoms the individual associates with their illness. Therefore, the IPQ-R was deemed more suitable for this study, as it examines the illness perceptions of specific dementia symptoms of people living with dementia and their help-seeking intentions.

Illness Perceptions and Dementia

When a person receives a diagnosis of dementia, they may already have their own beliefs about the illness. These beliefs are based on the information and experiences that are available to the individual. Sources of information can be assimilated from previous knowledge of dementia, symptomatic information from health professionals and social communication with others (e.g., family and friends) (Hagger & Orbell, 2003). A combination of these sources contributes to an individual "making sense" of their dementia and this representation is applied to create an individual understanding of the illness, thus potentially guiding a coping response (Leventhal, 1985).

Moreover, an interest of note is the issue of awareness in dementia among people living with illness, and its implications regarding a person's illness perceptions. People displaying mild symptoms of dementia will largely have a preserved illness awareness of dementia. However, they may not be able to translate knowledge about their symptoms (i.e., cognitive decline) into practical solutions (Glidewell et al., 2011, Clare et al., 2022). This is an important factor to consider when examining a person's illness perceptions as they may not understand the process of how to seek for help in relation to their dementia. Thus, the individual appraises the process to determine the failure or success of their specific coping strategy in response to their own perceptions of their awareness of having dementia (e.g., seeking help or not) (see Figure 1).

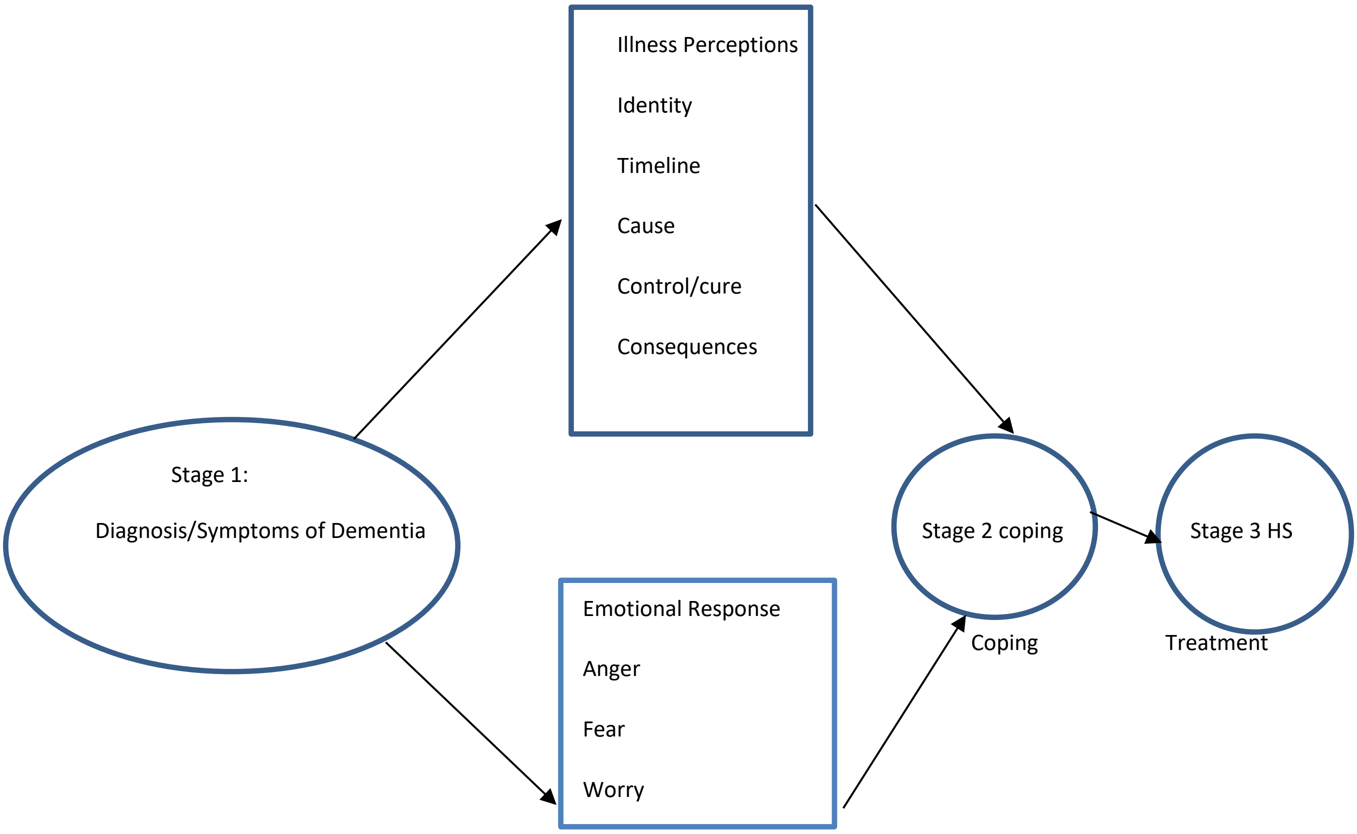


Figure 1

Model of Illness Perceptions Once Diagnosed with Dementia; Based on the Self- Regulatory Model of Illness Behaviour (Leventhal & Nerenz, 1985). HS=help - seeking

Self-Regulatory Model and the Illness Perception Questionnaire

The Self-Regulatory Model (SRM) (Leventhal & Nerenz, 1985) proposes that individuals base their illness representations on personal experience and outside influences. These representations can be defined as a person's own common-sense beliefs about their condition, which provide an individual with a structure for coping with and understanding their illness (Parveen et al., 2017). Examination of the psychometric properties of the IPQ-R has shown that high scores on the identity, consequences, acute/chronic and timeline subscales represent more strongly-held beliefs about the attribution of a condition's symptoms. Moreover, the symptom dimension of the IPQ- R scale has been applied and endorsed across various diseases (i.e., renal disease, rheumatoid arthritis, and multiple sclerosis) (Moss & Morris et al., 2002). Examples of this dimension within this study are to ask whether the individual has experienced a specific symptom such as anxiety since being diagnosed and if this symptom is related to their dementia. The initial cause dimension is not used as a scale, but a factor analysis can be used to identify groups of causal beliefs (e.g., stress, age) which then can be used as subscales. Individuals are asked what they perceive to be the cause of their illness, plus ranking the three most important factors believed to be the cause of their illness, with all answers summed to give an overall score (Moss-Morris et al., 2002).

Over the years a growing evidence base has sought to understand the SRM's utility in people with mental health conditions and a systematic review by Baines and Wittkowski (2013) concluded that the dimensions of cognitive and emotional representations are linked to variance in an individual's personal response and physical health outcomes. This suggests that understanding the variance in an individual's behaviour when it comes to health-related decisions can be useful for healthcare professionals and lead to improved health outcomes (Ryan et al., 2008). Moreover, studies that have utilised the SRM to examine health outcomes in patients with heart disease have endorsed the SRM as a useful theoretical model for informing interventions to reduce delays in help seeking (Matthews et al., 1983; Hall & Foushee, 1993; & Walsh et al., 2004). These studies show that symptom representation, denial, coping strategies, and re-appraisal were all linked to longer delays. As part of the appraisal process, it was found that patients who sought help from family and friends had reduced delay times for medical interventions (Pattenden et al., 2002). The SRM provides an understanding of how individuals evaluate and respond to their own health challenges. Thus, the appraisal process influences an individual's initial perceptions of the health threat, while the SRM explains how they regulate their behaviours to cope with the health threat effectively.

Within the field of dementia, several studies have explored perceptions of dementia and health beliefs in relation to help-seeking; however, the findings have been variable. For example, Roberts and Connell (2000) examined the attitudes and beliefs of close relatives of a person with dementia. They reported that < 70% were knowledgeable about Alzheimer's and that their perception of disease risk was accurate, and that symptoms of memory loss was indicative of Alzheimer's disease. However, as the data from Roberts & Connell (2000) study was not collected by a self-report method their perceptions could be described as being assessed as opposed to the accuracy of responses that are accepted within a self-report method. In contrast, Werner (2003) explored knowledge of symptoms of Alzheimer's disease among a sample of community participants (less than 50% had a friend diagnosed with Alzheimer's) and reported that only 47% considered repetitive and continuous memory difficulties as a sign of cognitive impairment or dementia. Moreover, Phillipson et al.'s (2015) survey of the Australian general public revealed that most people (82%) would seek help for early signs of dementia, and that fear of discrimination played a part in avoiding seeking help. This suggests that people's perceptions of dementia are much influenced by their own social experiences, and thus can vary (Leventhal et al., 1998). However, these studies are limited to collecting data from the general public, where researchers will have used standard assessment tools, whereas assessments of illness perceptions for people living with dementia will apply a more tailored approach. Also, surveys can provide insights into the prevalence of specific beliefs and allow for comparisons between different groups, but they also have limitations in capturing a more in-depth analysis of an individual's own experiences. Therefore, it is important to note that the findings from these studies may be in contrast to each other due to the different methods applied.

By applying the SRM, this study aims to build on previous SRM research and examine whether illness perceptions among people with dementia and their CGs predict their help-seeking intentions. Once a person is diagnosed with dementia, cognitive processes are involved in the interpretation and perception of symptoms of the disease (Qualls, 2015). As an individual forms their own perceptions of symptoms, they will identify with the symptom (e.g., memory loss, apathy), leading the individual to reassess their diagnosis of dementia and form their own representation of the illness. Therefore, how the patient perceives their diagnosis of dementia is crucial regarding how they deal with the disease and whether and how they seek help (Phillipson et al., 2015). Moreover, identifying factors that are associated with perceptions of living with dementia and the impact that the dyadic relationship has on these factors may contribute to improvements in future health interventions.

Contribution to Knowledge

Previous studies that have examined the effect of illness perceptions of dementia in relation to help-seeking are relatively rare and have mostly focused on the general public's perceptions (e.g., Hamilton West et al., 2010; Roberts et al.; 2014). Furthermore, only a small number of studies have explored the beliefs of people with dementia (Quinn et al., 2018). Moreover, the majority of these studies (i.e. Hamilton West et al., 2010, 2012; Shinman-Altman & Werner, 2019) have been qualitative and have shown that the person with dementia may attribute the cause of their illness to a variety of factors and use such terms as "memory loss" to refer to their condition rather than, for example, "Alzheimer's disease".

A study by Clare et al (2016) applied the SRM within a mixed methods model. The study examined illness representations among people with mild-moderate dementia and their CGs and the association between identity and cause of dementia and other participant characteristics. A cluster analysis revealed three profiles: an Illness cluster, where individuals saw themselves as having an illness and adopting a diagnostic label, an ageing cluster where individuals saw their dementia related to getting older and a no problem cluster where individuals did not see themselves as having any difficulties. These findings suggest that interventions aimed at people living with dementia may benefit from a more targeted approach in line with an individual's own representation profile.

More recently there has been research exploring the psychological processes to living well with dementia and how illness perceptions influence well-being among people with mild-moderate dementia (Clare et al., 2022). Clare et al's study explored predictors of specific groups and the association with well-being, and whether problem focused coping was a mediator within the process of association. Findings revealed four classes of dementia representations. The four classes were identified as: individuals who see dementia as a disease but refer to symptoms rather than a named diagnosis, individuals who see dementia as a disease and adopt a named diagnosis, those that see dementia as part of the ageing process and those that are not sure how to make sense of their dementia. Findings revealed that the association of well-being remained steady over two years. However, there was a little support for the mediating role of problem focused coping.

Even though these studies provide important information about illness perceptions and dementia, they do not examine the relationship between the illness perceptions of dementia to well-being and other outcomes such as help-seeking. Individual perceptions of dementia have the potential to impact on the help-seeking intentions of both the person with dementia and their CG. Most research in this area has focused on an individual approach, despite recognition of the need for more research to examine the dyadic effect (Braun et al., 2009). An under-researched area is how illness perceptions of dementia may influence help - seeking within the dyadic relationship of the person with dementia and their CG. To the best of our knowledge this is one of the few studies to utilise the IPQ-R in research with people living with dementia, and the only study to examine the dyadic perspective regarding the effect of illness perceptions of people with dementia and their CGs on their own help-seeking outcomes.

In support of a study examining illness perceptions and help-seeking in people living with dementia, previous studies examining the association between illness perceptions and health outcomes for other conditions (e.g., heart disease, arthritis, mental health) have proved to be beneficial in providing strong evidence that changing illness perceptions can modify behaviours. These studies have shown that interventions designed to change illness perceptions can improve the health outcomes of an individual by creating help-seeking behaviours to gain support with living with an illness (Broadbent et al., 2015).

Consequently, this piece of research will attempt to answer the question, what is the relationship between an individual's own illness perceptions and their own help-seeking intentions after receiving a diagnosis of dementia. It will also examine the effect of the dyadic relationship on an individual's own help-seeking. To answer these questions the theoretical framework of the self-regulatory model (SRM) (Leventhal et al., 1980, & Leventhal et al.,1997) will be applied. This will provide greater insight into how people construct their own beliefs of a diagnosis of dementia, and how their own health beliefs impact on their intention to seek help.

Structure of Thesis

The aim of this study is to examine the relationship between the illness perceptions and help-seeking intentions of people living with early-stage dementia and their CG and the effect of the dyadic relationship on their own Illness perceptions on their own help-seeking intentions.

This first chapter introduces the background to the research topic and defined key concepts in dementia and demographics. The chapter has also considered the role of the dyadic relationship, the challenges faced with caring for someone with dementia and the impact of living with dementia on seeking support within the wider community.

Chapter two contains the literature review, which systematically presents and discusses empirical studies in relation to the components of illness perceptions among people with dementia and their CGs, and the relationship with help-seeking.

Chapter three presents the methodology applied with an outline of the ontological and epistemological approach and the theoretical framework. Methodological choices are justified, and the self-regulatory model (SRM, Leventhal & Nerenz, 1985) is described.

Chapter four outlines the specific methods applied and describes how data was collected and analysed using the Actor Partnership Independence Model (APIM) (Kenny et al., 2006) and Multi-level Modelling (MLM). It also describes issues relating to reliability, rigour and the ethical considerations applied in this study.

Chapter five presents the findings of the study, notably the demographics of the sample, descriptives of the Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002) and the structure of the IPQ-R and its applicability for people with dementia and their CGs. Also presented is an overview of correlations between the IPQ-R and help-seeking, and findings from the analysis of the dyadic effect of illness perceptions on help-seeking intentions among people with dementia and their CGs.

Chapter six discusses the main findings from the study with reference to the literature review, the SRM and the APIM, and the useability of the IPQ-R for people living with dementia. Regarding key findings, this chapter provides a detailed discussion of correlations between the IPQ-R and the General Help Seeking Questionnaire (GHSQ) (Wilson 2005 et al.,). Also discussed is the actor and partner effects between identity and causal beliefs and help-seeking in relation to the APIM, plus the effect of confounders when added to the model.

The final chapter provides my own personal reflections on studying for my PhD. It also summarises key findings from this piece of research with future recommendations and contributions to knowledge within the field of illness perceptions of people living with dementia.

Chapter 2: Literature Review

The content of this chapter is also included in the published paper; Gregg et al. (2021). What is the relationship between people with dementia and their caregiver's illness perceptions post-diagnosis and the impact on help-seeking behaviour? A systematic review. *Dementia* Vol. 20(7) 2597-2617 DOI: 10.1177/1471301221997291.

The previous chapter defined key concepts in relation to living and caring for someone with dementia, the role of the caregiver (CG) and the dyadic relationship. It also outlined how illness perceptions can impact on help-seeking intentions of people living with dementia. Consequently, this review systematically presents and reviews the most relevant literature, with an aim to expand on what is known about the illness perceptions of people living with dementia and the impact on their help seeking.

Introduction

An early diagnosis can bring significant social, personal, and economic benefits, which can impact on improving the quality of life for people living with the condition (Perry-Young et al., 2018). Further, seeking out help for interventions, either pharmacological or psychological, at the earlier stages of the disease can be related to milder impairment. For example, a study by Tang et al. (2016) revealed that individuals with dementia who sought help later had worse depressive symptoms and neurological functioning than people who had received treatment earlier. Moreover, a study by Moon et al. (2017) revealed that CGs reported that the person with dementia was significantly less involved in decision making for daily support and valued social contact less than their CG.

Thus, the notion of accessing treatments for dementia care earlier rather than later is important and is at the core of Living Well with Dementia strategies from governments worldwide (e.g., UK Prime Minister's Challenge on Dementia, 2012). Good post diagnostic support for people living with dementia and their CGs can facilitate a better understanding of their condition, as people living with early-stage dementia can potentially plan for their future while still able to do so, enhancing their quality of life (Devoy & Simpson, 2016). However, once people are diagnosed, during the early stages of dementia, they and their CGs are often reluctant to seek help, as dementia still attracts a level of shame and stigma due to its links with diminished capacity, poorer mental health, and loss of independence (Herrmann et al., 2018).

To ameliorate this situation, this review summarises information about the association of illness perceptions with help-seeking intentions, as to provide a framework to understand the components that form an individual's illness perceptions once diagnosed with dementia. The role of Illness perceptions has long been acknowledged as an important part in responding to symptom recognition and self-management of diseases or conditions generally (Hagger & Orbell, 2010) and in relation to dementia specifically (e.g., Roberts et al., 2014). There have been several proposed definitions of illness perceptions, comprising of different models that include the cognitive and emotional components of a person's representation of their illness. For a more detailed presentation see Petersen et al. (2011). These processes are important as they can influence an individual's coping strategies once diagnosed, involving risk perception and psychological well-being.

The Self-Regulatory Model (SRM) (Leventhal, Meyer, & Nerenz, 1980) is a useful model for understanding the coping processes and beliefs relating to an illness. This model explains how individuals perceive their illness via cognitive representations, such as identifying with the disease, cause/control, consequences, coherence, and the emotional response to the illness (Shinan-Altman & Werner, 2019). Therefore, illness perceptions and their relationship to help-seeking are important determinants of the individual's management of their illness. Sometimes these lay representations will coincide with scientific orthodoxy and sometimes they will be at odds with more accepted beliefs around the condition. Thus, understanding how people make sense of dementia and its implications is an important issue when working with individuals as they come to terms with their dementia diagnosis (Harman & Clare, 2006).

A recent systematic review of help-seeking for dementia (Werner et al., 2014) examined non-professional and professional sources of help-seeking, with results showing a preference for seeking help from close family members and friends followed by primary health care services. However, this review did not explore the mechanisms implicated in the process of help-seeking, such as illness perceptions.

While research in help-seeking for dementia has been increasing, to the best of our knowledge, there has not been a review exploring how the person with dementia and their CGs illness perceptions impact on help--seeking intentions once diagnosed with dementia. Therefore, a clearer understanding of how people's illness perceptions and the relationship to help seeking once diagnosed may provide insight into an individual's attempt to manage the illness. Thus, the aim of this review was to provide a preliminary evaluation of the available literature (qualitative and quantitative) on the relationship between illness perceptions with help seeking with people diagnosed with dementia and their CGs.

The specific review questions are:

1) How do illness perceptions impact on the intention to seek help after a diagnosis of dementia?

2). How does a caregiver's illness perceptions impact on their intention to seek help for the person with dementia and for themselves?

Methods

Search strategy and selection of studies

The methodology applied for this review was based on the Evidence for Policy and Practice Information and Co-ordinating Centre Guidelines (EPPI-Centre; Oliver et al., 2005b), which was designed for wide-ranging research questions including both quantitative and qualitative evidence (Clement et al., 2014). The EPPI-Centre incorporates an initial scoping and mapping exercise to specify and prioritise any relevant studies. After conducting a scoping review, this revealed two main types of literature: qualitative and quantitative.

In line with the EPPI-Centre method, a parallel review was conducted for the quantitative and qualitative studies, with findings from both reviews brought together in juxtaposition in a meta-synthesis. The Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) checklist guidelines for the conduct of the findings was applied (see diagram 1). As this literature review incorporated a broad subject area, a search of general databases was conducted utilising: Cochrane Central Register of Controlled Trials (CENTRAL); Cochrane Dementia and Cognitive Improvement group (CD-CIG), ALOIS, and Centre of Reviews & Dissemination (CRD)], however this search did not identify any relevant studies; thereafter, more specific health related databases were searched. These were Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, Medline and PubMed. Furthermore, each individual database was searched with relevant subject headings from February 2018 to August 2018 and revised in October 2018. An adjacent search was conducted in April 2020. Search terms were identified in collaboration with a specialist librarian. The search terms used were dementia or “vascular dementia” or “Alzheimer’s” or “Lewy body” or “frontotemporal” and were applied as MeSH terms which produced > 94,000 hits. Thereafter the search was modified with search terms aimed to represent the primary concepts of “dementia”, “help seeking” and “illness perceptions”. Keywords entered were “Illness perceptions and Alzheimer’s and help-seeking” “Illness representations or help-seeking” “dementia and caregivers or help-seeking or illness perceptions”. Adjacent search terms were “Identity” or “control” or “cause” or “timeline” or “consequences” or “emotion” or “coherence” and “dementia” and “help-seeking” The search process was also enhanced by manual searching of reference lists. Experts in the field were also contacted for any ongoing/or unpublished studies. Additionally, grey literature was searched on electronic databases (Open Gray, BASE). Once papers were identified through this database search, the main reviewer (JG) screened titles and abstracts to assess eligibility.

Inclusion Criteria

- Studies that identified key terms in title, abstract or MESH headings were retained.
- Inclusion criteria were studies that explored relationships between illness perceptions and help-seeking intentions/behaviours for people diagnosed with dementia and their caregivers and receiving informal care in the community.
- The term 'perception' did not have to be applied, as studies looking at these associations can use other terms such as illness 'representations', 'cognitions' or 'beliefs'.
- Articles published in peer review journals and written in English.

Quality assessment

Before the quality assessment was conducted, an agreed standardisation of 80% level of agreement was considered acceptable between two reviewers (JG & RN). The second reviewer, RN, is a consultant psychiatrist specialising in dementia. The two reviewers independently assessed the qualitative studies applying the Critical Appraisal Skills Programme (CASP: 2018) checklist assessment tool. The main reviewer (JG) assessed all qualitative studies, with the second reviewer (RN) independently assessing a random sample (*n* = 5) of papers and clarified inconsistencies with the main reviewer for rigour and suitability for the review. The CASP checklist was designed as a tool within educational workshop settings thus a scoring system is not recommended; moreover, this format has been deemed appropriate for assessing qualitative studies (CASP, 2018).

For the quantitative studies methodological quality was also assessed (JG & RN) by using the cross-sectional survey checklist (Centre for Evidence Based Management 2014, adapted from Crombie 1996). The main reviewer (JG) and second reviewer (RN) independently assessed studies using checklist criteria and resolved discrepancies through mutual discussions. Figure 1 details the final selection of studies.

Data extraction strategy

Data from all studies were extracted by the main reviewer (JG) using a data extraction tool adapted from Egan et al (2003). Standard study characteristics were extracted, plus details of study design, outcome measures and main findings. Using this tool aided in the collating of data from selected papers and helped identify differences and similarities in terms of key findings and methodology.

Data Synthesis

Findings were synthesised applying standard methods for narrative synthesis (Popay, 2006). Narrative synthesis was utilised as there was a substantial clinical and methodological heterogeneity between all studies. Moreover, a meta-analysis was not deemed appropriate as heterogeneity was considerable across selected studies in respect of primary outcomes, types of dementia and cultural differences. Therefore, the analysis incorporated a compare and contrast approach by conducting a comprehensive juxtaposition of review findings across all identified studies (Popay, 2006). Additionally, a tabular presentation of the characteristics of the identified studies was included to support the narrative and to aid in identifying patterns across the data (see tables 1.4 & 1.5 in appendix 1).

Data Analysis

Qualitative studies were analysed by the main reviewer (JG), adopting a thematic analysis (Braun & Clarke, 2006). Thematic analysis provides a tool to analyse and identify themes unrestricted from any theoretical undertakings and has been applied successfully when synthesising various data sets, enabling flexibility within various theoretical paradigms (Bunn et al, 2012). Illness perception dimensions were noted by identifying recurring and prominent themes and allowed for categories to emerge from the data. This process allowed for grouping and regrouping of relevant data associated with illness perceptions. Thereafter data were revised to identify inter-related themes and sub themes across and within the data set to form a final set of emergent themes (Clarke & Braun, 2017).

Quantitative studies were also analysed by the main reviewer. For quantitative studies, values representing the association between perceptions/cognitive processes and help seeking were extracted, and illness perceptions grouped into identity, cure/ control, cause, consequences, coherence, and emotional representations (Leventhal & Nerenz, 1985)]. The relationship between illness perception dimensions and reported outcomes was based on an examination of the author's interpretations of data specific sets that supported the relationship and its direction (Clement et al 2015).

Findings of Included Studies

As noted in figure 2, a search of databases was completed and yielded 275 references. Thereafter 31 additional references were identified via other sources. After removal of duplicates and studies that clearly did not meet the inclusion criteria, 192 full text records were retrieved. Of these 192 records, a further 134 were excluded at this point as not being relevant, leaving 58 full text references to be assessed further for eligibility. Of these remaining records, 44 studies were excluded as they did not meet all the inclusion criteria. Therefore, 14 studies were eligible to be included in this review. Nine studies were qualitative and five were quantitative. See Figure 1 for PRISMA flow chart diagram of search process.

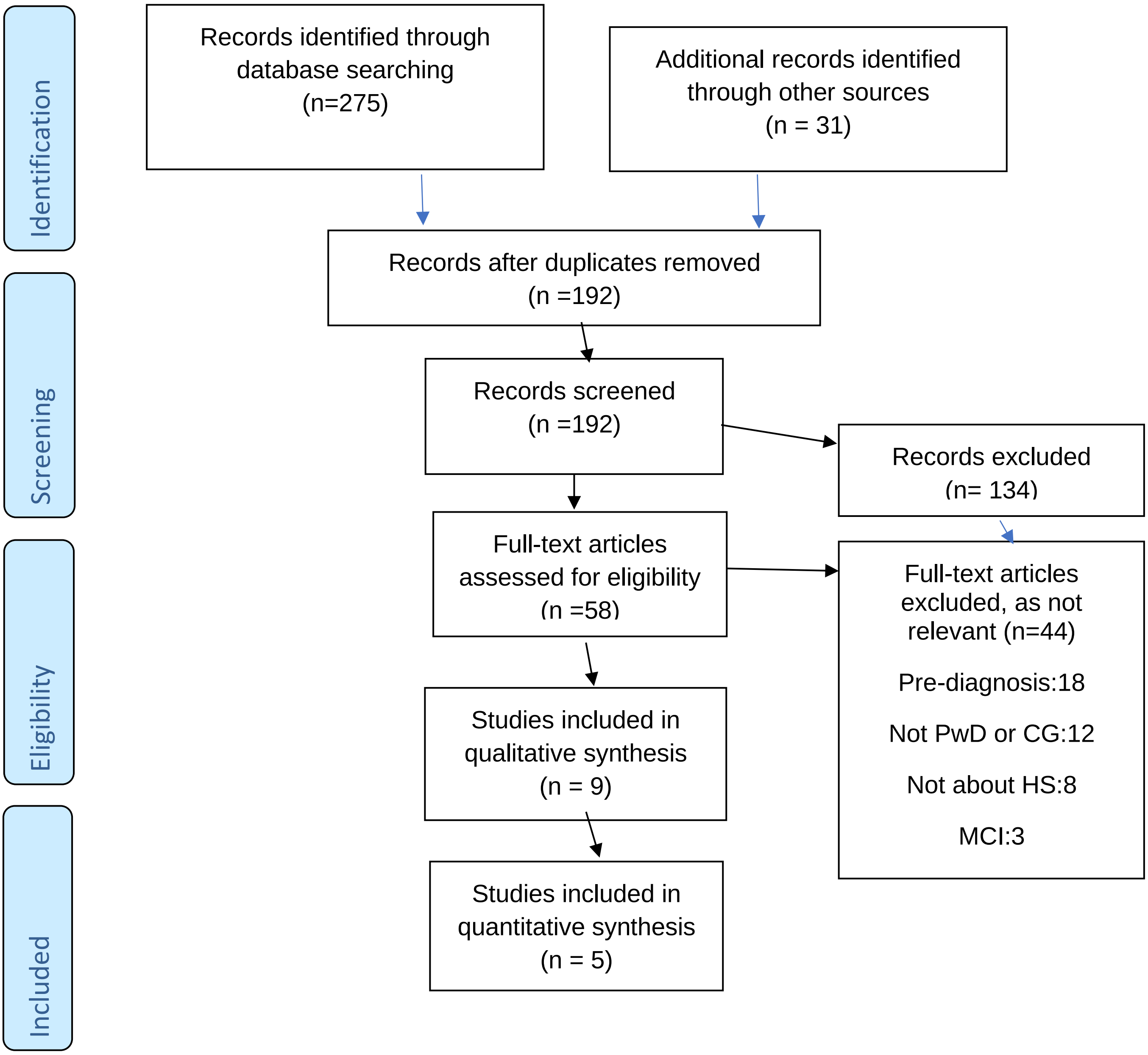


Figure 2

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. MCI = Mild Cognitive Impairment; HS= Help seeking, CG = Caregiver, PwD = People with dementia

Study and participant characteristics

The selected studies were from various backgrounds (psychology, psychiatry, public health, mental health nursing and dementia) and included articles from various countries. In summary seven studies were US based, two UK based, two Australia based, and there was one study each from China, Hong Kong, Vietnam, and Europe (eight European countries in total, including the UK). In relation to study settings, community-based scenarios were day care units, dementia clinics, support groups and a roadshow). For participants recruited into the studies, 11 studies involved CGs, with only three investigating people with dementia as well as their CGs. Regarding the approach applied for data collection for the qualitative studies, four applied semi structured interviews (Mukadam et al., 2011, Au et al 2013., Haralambous et al., 2014, Peterson et al., 2016), two focus groups (Braun, Takamura, & Mougeat, 1996, & Stephan, 2018), one an unstructured interview, (Brown et al., 2007), one was descriptive (Braun & Browne, 1998) and one employed a roadshow/discussion format (Parveen, 2017). For the five quantitative studies, four applied a survey design (Smyth & Milidonis, 1999, Hinton et al., 2006, Valle, Yamada, & Barrio, 2010, & Phillipson et al., 2013) with no follow up, one was a longitudinal survey (Cox, 1999) with two follow up evaluations over a 12-month period (Tables 4 & 5 gives a more detailed outline of study characteristics).

Quality appraisal: Qualitative Studies (n = 9)

The CASP (2018) checklist tool assessed for quality regarding justification for methods used, data source collection and analysis, and all studies were considered appropriate. However, most studies (*n* = 6) did not either report informed consent procedure or confidentiality processes. Moreover, all included studies did not adequately describe the relationship between the researcher and participants, with no reflection on any potential influence regarding collecting and analysing data. Only two studies (Haralambous et al., 2014, and Parveen et al., 2017) applied a theoretical framework. Table 1 reports on the methodological issues for all included qualitative studies.

Table 1

Methodology Issues for Qualitative Studies

Reference	Design	Methodology issues
Braun et al 1996	Focus groups – audio taped	No mention of informed consent.
Brown et al 2007	Face to Face Unstructured Interviews- audio taped	Convenience sampling. Participants recruited through support groups and personal contacts. Possibility for potential bias.
Mukadam et al 2015	Face to Face Semi-structured interview- audio taped	Purposive sampling. Carers approached by clinician they knew. No mention of informed consent/ confidentiality. Participants sent transcripts and invited to comment on accuracy.
Au et al 2013	Face to Face Semi- Structured Interview – audio taped	Convenience sampling-no mention of researcher role in study.
Haralambous et al 2014	Face to Face Semi-structured Interview- audio taped	No mention of informed consent/ confidentiality.
Stephan et al 2018	Focus groups	Sampling procedure- not described adequately, participants contacted by gatekeepers: support groups and known contact persons from other parts of the project. No mention of informed consent/confidentiality.

Quality appraisal: Quantitative studies (n=5)

By utilising the cross-sectional survey checklist (Crombie, 1996), all studies applied measures that were reliable and valid. Furthermore, the samples utilised in all the studies were representative of the sample by reflecting similar characteristics among the population being researched. Additionally, only one study (Phillipson et al., 2013) reported confidence intervals (CI) for main results and only two studies (Phillipson et al., 2013 & Cox, 1999) clarified the theoretical framework. Table 2 below outlines the methodological issues for the quantitative studies.

Table 2

Methodology Issues for Quantitative Studies

Reference	Model	Methodological Issues
Cox 1999	Andersen & Newman (1973)	No CI reported, limitations not reported
Smyth & Milidonis 1999	Not stated	No CI reported, decision for sample size not reported
Hinton et al 2006	Not stated	No CI reported, small sample size (n=38) in relation to epidemiological standards of Latino American people living with dementia
Valle et al 2004	Not stated	No CI reported, cultural issues not taken into consideration
Phillipson et al 2013	Andersen & Newman (1973)	Confounding factor of culture not reported.

Emerging themes across all studies

The subthemes identified in the qualitative studies were also apparent in the quantitative studies. By comparing and contrasting findings across all studies, the five following themes were identified. Most frequent rated themes that emerged (>5) are presented in a tabular format in Table 3. Tables 4 and 5 describes the main study characteristics.

Table 3

Identified Themes in Relation to Illness Perceptions

Illness Perception	Theme	Sub Theme
Identity/cure/control	Duty of care	Cultural beliefs/ stigma
Cure/control/ emotional representations/	Threat to independence	Hindrance or help
Consequences/ emotional representations/Coherence	Complexity of system	Response from health professional (HP). Negative & positive experiences
Coherence/Identity/cause	Lack of Knowledge	Symptoms & cause
Identity/cure/control/ emotional representations	Acceptance of diagnosis	Emotional wellbeing/ consequences

Table 4

Study Characteristics of Qualitative Studies

Reference	Objective	Design	Sample	Setting	Analysis	Illness Perceptions/Themes	Outcomes
Braun et al. 1996	To explore perceptions of Vietnamese immigrants in the USA, regarding caregiving and help seeking of a PwD	Focus groups	Four groups. Mean number in groups = 11.5: Men (mean age 65.2) Women, (mean age = 55.6) Youth (mean age = 23.8) & Mixed groups of CG of person with dementia (mean age = 54.0)	Community-Vietnam	Not mentioned	Identity, consequences, control: Duty of care-Cultural beliefs	Results reported importance of hierarchy family structures in the Vietnamese population, with a low priority of dealing with dementia when facing problems associated with caring, and a willingness to access services.

Braun & Browne 1998	Presents information on how cultural values & practices affect perception of dementia, caregiving and help seeking	Descriptive	Asian Pacific Islanders (API) Age not reported.	Community- USA-	Descriptive	Identity, control, emotional representations: Duty of care-Cultural beliefs/stigma	Cultural beliefs can affect individuals asking for help, this can be seen as a weakness. Family norms dictate the beliefs around responsibility to care for person with dementia.
Brown et al. 2007	To gain an understanding of help seeking process of older husbands CG of wives with dementia	Unstructured Interviews	9 CG of persons with dementia mean age = 79 yrs., range 65-87 yrs.	Community- USA	Grounded Theory	Consequences, cure/control: Complexity of system- Negative & Positive experiences	Main findings were that attitude, values, & experiences influenced choices made, especially the influence of negative previous experiences with care providers,
Mukadam et al. 2011	To explore link between attitudes to help seeking for dementia in minority ethnic (ME) people and	Semi- Structured Interviews	18 Caregivers (CG) of person with dementia. Mean age = 57 yrs.	Community- UK	Thematic analysis	Identity, cure/control: Duty of care-Cultural beliefs/stigma	All carers seemed to identify early symptoms of dementia, however barriers to early help seeking in the ME population was that a dementia diagnosis was of no use, and that it was

	the indigenous population						a family's duty to care for person with dementia.
Au et al. 2013	To explore coping & help seeking behaviour among Hong Kong CG of PwD	Semi - Structured Interview	11 CG of persons with dementia. Age range = 43-83 yrs.	Community Hong Kong	Grounded Theory	Emotional representations: Complexity of system-Experiences & Response from Health Professional (HP)	Internal regulation, forbearance and family obligations are linked to not seeking help earlier. Chinese CG may be hesitant about disclosing information and seeking help, as were found to approach family for help rather than HP.
Haralambous et al. 2014	To determine barriers and enablers to accessing dementia services among older Asian PwD	Semi - Structured Interview/ Cultural Exchange Model	12 CG of person with dementia Mean age of Chinese CG= 54 yrs Mean age of Vietnames	Community- Australia	Cultural Exchange Model	Identity, cure/control: Complexity of system-Negative positive experiences	Barriers to accessing services included complexity of health system, language barriers and lack of knowledge about dementia.

	in Melbourne.		e CG = 62 yrs.				
Peterson et al. 2016	To understand complex determinants that lead CG of dementia need for education & assess barriers to seeking help	Semi - Structured Interview	27 persons with dementia & CG. Mean age of CG = 58 yrs. Mean age of PwD = 79.8 yrs.	Community-USA	Content Analysis	Identity, cure/control/consequences: Lack of Knowledge-symptoms and cause	Barriers to seeking help were linked to knowledge gaps about dementia, rather than reluctance to assume CG role. More public education for CG's for person with dementia is needed.
Parveen 2017	To explore perceptions of dementia and use of services among various ethnic community	Roadshows/discussion groups. Self- Regulatory Model (SRM)	175 persons with dementia, carers and community members. Age not reported.	Community-UK	Thematic & Framework Analysis	Identity, cause, emotional representations: Threat to Independence-Hindrance or Help-Cultural beliefs	Seeking help from services seen as a hindrance, linked to a lack of awareness about dementia and cultural barriers such as religious beliefs & language.
Stephan et al. 2018	To explore barriers & facilitators to access formal dementia care	Focus groups	147 persons with dementia & CG. Mean age of person	Community-8 European countries	Content Analysis	identity, cure/control/ consequences: Lack of Knowledge-Symptoms & Cause	Formal care be a threat to an individual's independence by the PwD. Health Professionals seen as key contact.

		with dementia = 76 yrs. Mean age of CG = 63 yrs.		

Table 5

Study Characteristics of Quantitative Studies

Reference	Objective	Design/Measures	Sample	Setting	Analysis	Illness Perceptions/Themes	Outcomes
Cox 1999	Exploring experiences of African Americans (AA) & White CG seeking assistance for person with dementia.	Longitudinal/ Survey/ Anderson Behavioural Model ADL, IADL CES-D	300 CG of person with dementia. 150 white CG, Mean age = 57 yrs, 150 AA mean age = 54 yrs.	Community-USA	Chi Square/t-test/contingency analysis	Cure/control, consequences: Acceptance of diagnosis/emotional wellbeing.	Both groups showed symptoms of clinical depression. Primary reason for seeking help was to obtain information on dementia. With significantly more AA calling for home help (<.001) or day care (p<.001), while more white CG (p<.05) called about support groups.
Smyth & Milidonis 1999	Study the relationship between exploration of service use, normative beliefs and help seeking	Survey/ Psychological Scales : CATSI, COO & PIC	120 CG & person with dementia, Mean age of CG = 67 yrs.	Community-USA	ANOVA/ Correlation	Consequences/emotional representations Acceptance of diagnosis/emotional wellbeing/consequences (captivity).	3 subscales significantly correlated: BCI & CFO (*r* = .32, P<.001) BCI & PIC (*r* = .61, p<.001) CFO & PIC (r =.22, p<.01). Normative beliefs regarding accessing help were significantly positively associated with CG physical and mental health.
Hinton et al. 2006	To examine dementia neuropsychia	Survey/ Neuro Psychological Scales NPI, CES-D & ADL	38 CG of persons with	Community-USA	Chi- Square	identity: Complexity of the System- Responses	CG perceived unmet needs for professional help in relation to specific

	tric symptoms severity and help seeking patterns		dementia. Mean age = 70 yrs.			from HP, negative a& positive experiences	NPI symptoms (75% disinhibition, 66.7% delusions). 80% of CG had seeked help for at least one neuropsychiatric symptom.
Valle et al. 2004	Ethnic differences in social network help seeking strategies	Survey/Psychological Scales: ASSIS, MBC & WOC-R	89 persons with dementia & CG. Euro-Americans n=50, mean age of CG = 69 yrs. Latino n= 39, mean age of CG = 57 yrs.	Community-USA	Chi-Square/ t-test/Multiple Regression	Cure/control, emotional representations: Duty of care- Cultural beliefs	Accounting for 21% variance of social network help seeking, the relationship between ethnicity and help seeking was moderately strong b= -3, p= 0.04
Phillipson et al. 2013	Why carers of PwD do not utilise out of home services	Survey/Psychological Scales : ZBI, ADL & CES-D. Anderson Behavioural Model (ABM)	152 CG of persons with dementia. Mean age of CG = 66.36.	Community-Australia	Univariate analysis /chi-square t-test	Cure/control, emotional representations: Lack of knowledge- Symptoms & Cause.	Beliefs that service use would result in negative outcomes for persons with dementia were strongly associated with non-use of day care (OR 13.11 95% CI (3.75, 45.89) and respite care (OR 6.13 95% CI (2.02, 18.70). ABM accounted for 67-42% variance in non-use of day centres.

Note: CATSI= Caregiver for Attitudes toward Services Inventory; BCI = Belief in Caregiver Independence; PIC = Preference for Informal Care; CFO= Concern for family opinion (Collins et al 1991); COO= Concern for the opinion of others; ASSIS= Arizona Social support Interview schedule (Barrio 2000) MBC= Memory & Behaviour checklist (Zarit et al 1985); WOC-R = Ways of Coping Revised (Vitaliano 1985); ZBI= Zarit Burden Inventory (Zarit 1998), ADL= Activities of Daily Living ; IADL= Independent Activities of Daily Living; (Zarit & Zarit 1987) NPI=Neuropsychiatric Inventory Scale (Cummings et al 1994) ; CES-D =Centre for Epidemiological Studies Depression Scale (Radoloff 1977) PwD = Person with Dementia, CG = Caregiver, AA = African American, ABM= Anderson Behavioural Model (Anderson & Newman 1973), SRM= Self-Regulatory Model (Leventhal et al 1980).

Qualitative Studies

The synthesis of qualitative studies produced findings relating to the illness perceptions of individuals and their identifying symptoms of dementia and the relationship of these to cultural beliefs and their impact on help-seeking (Braun & Browne 1998, Valle et al 2004, Mukadam et al., 2015, Au et al., 2013, Parveen, 2013). One major theme related to cultural beliefs was the perceived consequence and the acceptance of duty of care from the caregivers (CG's). Seeking help can be construed as a weakness, thus an unwillingness to seek help can be formed within an individual's own perception of the consequences of caring for someone with dementia. This was noticeable in studies by Braun et al. (1996) and Braun and Browne (1998). They reported that Asian family hierarchal structures (i.e., duty to pay back to elders) influenced how people interrelated within their role as CG. CGs own illness perceptions on the causes of dementia was seen as being attributed to normal aging and within the family network went unnoticed. Moreover, perceptions of accepting a diagnosis of dementia were highlighted by Braun et al. (1996) and Braun and Browne (1998). These specific cultural beliefs can impact on seeking medical help, whereas CGs would only consider taking a person with dementia to a clinician if dementia symptoms were severe, in the belief that nothing could be done to cure them (Braun et al., 1996, Braun & Brown, 1998).

Secondly, findings revealed that an individual's perception of the breadth of the concept of dementia could be an overwhelming experience for the person with dementia and the CG (Brown et al., 2007, Au et al., 2013 & Haralambous et al., 2014). This lack of understanding about dementia could exacerbate the development of a coherent illness identity and could impact on an individual's decision not to seek help. Furthermore, the quality of care experienced previously from health professionals could influence an individual's tendency to seek help or not. If individuals had a negative experience, engagement became more difficult, and professionals were rebuffed. Negative beliefs about residential and respite care were associated with non-use of these services. (Haralambous et al., 2014, Stephan et al., 2018).

Themes around an individual's perception of the lack of controllability and coherence of dementia and the threat to independence in the context of living with dementia at home were apparent in papers by Stephan et al. (2018) and Peterson et al. (2016). In particular, the study by Stephan et al. (2018) reported that people's attitudes and beliefs towards a diagnosis of dementia could impact on how they accepted the disease and then their subsequent use of formal care. These beliefs were reported as a major hindrance across all of the eight countries included in the paper, suggesting that the person with dementia may lack insight into the symptoms associated with the condition and therefore lack awareness of their needs in respect of asking for help.

Quantitative studies

Findings from the three association studies (Smyth & Milidonis 1999, Valle et al., 2010, Phillipson et al., 2013) produced mixed conclusions. The study by Smyth and Mildonis (1999) reported a positive correlation among normative beliefs, derived from the CG's own standards of caregiving and their relation to help seeking. CG's perceptions of the coherence of dementia and their own health were not significantly correlated to direct care tasks involving formal help providers, suggesting that help seeking was not influenced by CG's own perception of cause and coherence of the severity of dementia symptoms. However, the quota of care tasks involving seeking help from formal helpers was marginally inversely correlated with Belief in Carer Independence (BCI) suggesting a small effect size. Despite the considerable variation of normative beliefs regarding the role of CG's and help seeking, there was a limited association between these beliefs and patterns of help seeking. For example, with belief in carer independence (BCI) associated with carers' feelings of being trapped, but preference for informal care (PIC) and concern for family opinion (CFO) was not. This suggests perceptions of the consequences of caring for someone with dementia can affect help seeking.

Valle et al. (2004) reported significant differences in caregiver experiences, with the strength of relationship between ethnic groups (Latino and Euro- American) and help-seeking moderately strong (ethnic group factor explained 22% of variance of the dependent variable). Moreover, ethnicity was the only significant variable related to social network help seeking. Despite the strength of these associations between ethnicity and help seeking, the total model only accounted for 20% of variance in social network seeking scores which can be interpreted as a small effect size. Phillipson et al (2013) used an expanded version of the Anderson Behavioural Model (ABM) (Anderson & Newman, 1973) to identify associated factors (health beliefs, perceived needs, and social structures) with non-use of services. The ABM accounted for 42% of the variance in non-use of residential respite care and 67% for non-use of day care. This suggests that negative illness perceptions relating to controllability of the disease and emotional representations of CG's could result in negative outcomes for the person with dementia, as both were strongly associated with non-use. Overall, the model accounted for two thirds of the variation of non-use of day care in relation to people's perception of community services for dementia which can be interpreted as large effect size.

Cox (1999) and Hinton (2006) investigated frequency distributions and patterns of use of services (i.e., professional help, support groups, day care). Cox's study was the only longitudinal study over 12 months. Findings suggest that frequencies for both groups (African Americans [AA] and White caregivers) who sought support from services were similar (approximately 50% across both groups). The primary reason for seeking help was to obtain information on dementia, suggesting that attempts to create a coherent understanding of the disease facilitated help seeking. However, significantly more of the AA group requested day care compared to white CG's who enquired about support groups. Hinton's paper reported that a high percentage of CG's (80%) had sought help for at least one dementia symptom, with patterns of help-seeking demonstrating that CGs reported disclosure of symptoms to the care recipient primary care provider. Furthermore, in Hinton's study (2011) there were high levels of unmet needs for behavioural problems with >68% of CG's expressing a need for emotional support (counselling and information related to dementia). However, there was considerable variation in GG's rates discussing neuropsychiatric symptoms with their family doctor, with 57% of GG's disclosing information about inappropriate elation, to 100%

disclosing information about hallucinations. This suggests that a CG's perceptions of the identity (symptom profile) of dementia can impact on what kind of help is sought.

Discussion

This review sought to provide a narrative account of how the illness perceptions of people with dementia and their CGs can impact on their tendency to seek help post diagnosis. This review presents findings of 14 publications of which nine were qualitative and five were quantitative, with all studies exploring help seeking among people with a diagnosis of dementia living in the community. In contrast to previous reviews that examined the help-seeking intentions of people experiencing symptoms of dementia pre diagnosis (Werner et al., 2014, Perry-Young et al., 2018), this review focused on help seeking once diagnosed. By synthesising the results from both qualitative and quantitative studies, a general consensus revealed that illness perceptions and the separate components that form these perceptions (symptoms/identity, cure/control, cause, consequences, coherence, and emotional representations) were associated with barriers and facilitators to help-seeking. These included strong cultural beliefs about symptoms of dementia, associating the disease as part of the ageing process. Also, inadequate knowledge and beliefs about dementia (coherence), and previous experiences of health care services (emotional representations, consequences), caused difficulty in identifying the symptoms of dementia and acceptance of a diagnosis (symptoms/cause/control).

Regarding quantitative studies, three of the five selected studies were association studies and, of these, two reported magnitude of effect sizes in relation to help - seeking intentions and an individual's beliefs of dementia. Even though the sample of papers reviewed was small, findings were variable. Studies including frequencies and patterns of help-seeking indicated that CGs were forthcoming in asking for help, specifically regarding information seeking. However, they also reported that the emotional burden of caring for someone with dementia could be a barrier for CG's regarding disclosing their own emotional distress for fear of being seen as unable to cope.

These findings were echoed in the qualitative synthesis process, where sub-themes of emotional wellbeing and consequences were identified. These sub-themes of emotional wellbeing, consequences and duty of care demonstrated how illness perceptions in relation to the stigma associated with caregiving may deter help seeking by various means. For example, that people were willing to dismiss the label of receiving formal care, as to avoid the public stigma this attracts, and the desire to avoid internalised feelings of embarrassment and shame (Corrigan, 2004).

Our findings show that individuals' illness perceptions of dementia can contribute to a person's help-seeking behaviour, with this review demonstrating the importance of cultural differences within approaches to help seeking, and how tailored interventions could be beneficial to individuals living away from their country of birth. However, it would also appear that people's perceptions of their understanding of dementia, in relation to accessing health care, can impact on an individual's tendency to seek out help. Also, there was reported instances of delays due to clinicians not identifying CGs issues of carer burden, and a lack of awareness, knowledge, and trust of dementia services.

A consensus from the studies reviewed is that people living with dementia only seek help when the symptoms start to become more severe. This suggests that an individual's own perception about the severity of dementia can influence the time to seek out help. Barriers to seeking help are lack of knowledge and one's own personal beliefs of dementia symptoms, suggesting that education about seeking help early on for dementia, rather than later, is much needed.

These findings seem to support previous literature on help-seeking for dementia (i.e., Werner, 2003, Werner et al., 2014, Perry Young et al., 2018) and suggest that help-seeking is a complex process that not only depends on the primary diagnosis, but also how the individual makes sense of these changes. These illness perceptions are formed over time, suggesting the intention to seek help is part of a much longer process, as people come to terms with living with dementia (Perry-Young et al., 2018). As diagnostic procedures are becoming more available, it would seem advantageous for primary and community care services to offer interventions post diagnosis to avoid further crises later (Burns, 2012).

Limitations

A strength of this review is the inclusion of qualitative and quantitative studies, with a broad representative sample. However, we cannot disregard the possibility that some studies may have been missed due to publication bias (significant results more likely to be published). Furthermore, information was synthesised and reported in summary tables with no statistical techniques applied for examination of methodological issues. However, it should be noted that this review was intended to focus on methodological and conceptual developments and the impact on future clinical interventions and research, rather than an exhaustive review of the literature. Although inter-rater reliability was utilised for assessing the quality of studies, the data search, extraction, and analysis were conducted by the first author, which may have influenced the dentification of criteria used for initial inclusion of studies.

Implications for Practice

How people adapt and respond to a diagnosis of dementia is highly determinative of their future care, demonstrating that people's perceptions of living and caring for someone with dementia can be an overwhelming experience. Therefore, it would be beneficial if a collaborative approach between health and social care sectors developed interventions after the initial diagnosis, to engage people who are hard to reach (Aldridge, Burns, & Harrison-Denning 2019). Engaging people from the outset and supporting them as they adapt to living with dementia may encourage people to have a clearer understanding of the disease. Importantly, findings have shown that there is a delay in seeking help from community services once diagnosed with dementia, due to a lack of trust in dementia services and, as people can be referred to primary care after a diagnosis, a breakdown in communication can occur. After an initial diagnosis, there is little clinicians can offer under community mental health services, suggesting a need for more support at this time point by incorporating a more joined up process at the early stages of diagnosis and subsequent care from the family doctor. Receiving a diagnosis of dementia can be a daunting prospect for the person with dementia and their CG, with people displaying feelings of hopelessness. Thus, an individual's own illness perceptions on dementia can influence their choices and contribute to their help-seeking behaviour.

Conclusion

This review set out to explore and understand how people with dementia and their CGs seek help after a diagnosis of dementia in relation to their own illness perceptions. In summary, studies in the area of help-seeking and dementia have been increasing over the past two decades, indicating a greater interest in an understanding of this concept, however, there remains a gap in the current literature. This review highlighted how the components of illness perceptions and their association with cultural beliefs, lack of knowledge, stigma, acceptance of the condition and experience of services for dementia care can all play part in effecting how people seek out help. However, these processes are formed over time and as people balance their own beliefs and cognitions with the acceptance of living with dementia, the need to seek out help is a long process, rather than occurring at one single time point (Perry -Young et al., 2018). Furthermore, given that stigma can impact on help-seeking (Clement et al., 2014), developing strategies to reduce stigma related issues needs to be addressed. A number of interventions do exist, aimed at effecting, for example, societal and individual change (Link & Phelan, 2006). Moreover, only three studies explored the person with dementia's illness perceptions with help-seeking, with the relationship between the person with dementia and the CG not considered, suggesting that more research is needed in this area. Therefore, it would seem advantageous for future research to develop interventions addressing the factors highlighted in this review, in respect of the long-term effects of living with dementia in the community.

Chapter 3: Methodology

Introduction

In response to the findings reported in the systematic literature review, this research was conducted to examine the impact of illness perceptions on help-seeking intentions for people living with dementia. The decision to conduct a systematic review as opposed to other review methods was deemed appropriate as dementia is a global health issue, affecting populations worldwide. Also, the findings can be generalised across settings, populations, and variations in treatment regimens. By applying a systematic review allowed us to establish whether the findings were consistent, and to provide a replicable and more transparent process. Moreover, due to a relatively small number of published papers identified as being applicable, quantitative, and qualitative studies were combined to answer the same overlapping review questions. This process provided a much better understanding and deeper insight of the results obtained (Bryman 2016). Thus, the main aim of this review was to minimise any bias and report a comprehensive account of the relevant literature within the field of illness perceptions of dementia and the impact this has on an individual's help seeking intentions.

This chapter seeks to describe the study framework and rationale for the methodology utilised for this study. One of the findings from the systematic review revealed that once people receive a diagnosis of dementia, their help-seeking behaviour can be influenced by their own individual perceptions of the disease. This can have an impact on the relationship between the person with dementia and the CG, also effecting their own illness perceptions, and therefore requires further investigation. The main themes identified in the systematic review were cultural differences, stigma, threat to independence, lack of trust in services and lack of education and knowledge of dementia. The review also highlighted that people's responses and adaptations to living with dementia is formed over time and that, once diagnosed, interventions would be most beneficial earlier rather than later.

However, generally there was very little research exploring this area, and even less applying quantitative measures(n=3). Moreover, to the best of our knowledge the IPQ-R has not been used before with people living with dementia, thus justified our decision to apply the chosen methodology. Regrettably, most research examining an individual's perceptions of dementia has focused on the carer, and this was highlighted in the literature review with only three studies involving the person with dementia. Furthermore, even less studies have focused on the perspectives of both the carer and the person with dementia within the context of the dyadic relationship (Braun et al., 2009, Moon & Adams 2012). Therefore, the main aim of this research is to examine the effects of the dyadic relationship of the carer and the person with dementia illness perceptions with their own help seeking intentions. To address this concept the Actor Partnership Interdependence Model (APIM, Cook & Kenny 2005) was applied. The APIM integrates the conceptual view of interdependence in relationships that consist of two members (e.g., CG and person with dementia). Furthermore, the APIM is being increasingly used as an analytical method for people living with dementia, and memory problems (Lingler et al., 2016, Moon et al., 2017, Gellert et al., 2018).

Justification for the ontological and epistemological approach adopted will be offered along with the choice and design of the methods used.

Aims and Objectives

The general aim of this study was to examine the association of illness perceptions and help-seeking intentions in people with early-stage dementia and their caregivers (CGs) in respect of help-seeking for themselves, both as an individual and within a dyadic relationship (the person with dementia and the CG). The self-regulatory model (SRM) (Leventhal & Nerentz, 1985) was utilised as the theoretical framework to investigate this concept. Illness perceptions were examined in relation to the person with dementia seeking help for themselves after being diagnosed, and the illness perceptions of the CG in relation to seeking help for themselves. Also examined was the impact on the dyadic relationship within and between the person with dementia and CG on their illness perceptions and help seeking intentions utilising the Actor Partnership Independent Model (APIM, Kenny et al., 2005). The actor effect being the effect of the individual’s own illness perceptions on their own help seeking, and the partner effect being the effect of the partner’s illness perceptions on their own help-seeking. Examination of the association of Illness perceptions and help-seeking was incorporated into a quantitative cross-sectional survey and aimed to test the hypotheses given below.

Research Hypotheses

1. It was predicted that the illness perceptions of individuals with early-stage dementia would impact on their own help-seeking intentions, after controlling for quality of life, anxiety, and depression. Thus, individuals who reported more strongly held beliefs of dementia would influence the person with dementia inclination to seek help for themselves.

2. It was predicted that the illness perceptions of caregivers of people with dementia will impact on their intention to seek help for themselves after controlling for quality of life, anxiety, and depression. Thus, individuals who reported more strongly held beliefs of dementia would influence the caregiver’s inclination to seek help for themselves.

3. It was predicted that the illness perceptions among dyads (the person with dementia and the CG) will influence the help-seeking intentions of dyad members, after controlling for quality of life, anxiety, and depression, and be present at the interpersonal and intrapersonal level.

Research Paradigm

To support the aims and objectives of this study, the ontological perspective of realism (where reality exists independent of the researcher) was considered and subsequently used based on an assumption that a discoverable reality exists independent of the researcher (Scotland, 2012). Realism maintains that there is an external reality that exists and can be know or studied through objective observation, and that by testing a theory and identifying a specific hypothesis, the data collected will either support or reject the hypothesis (Creswell, 2003).

Crotty (1998) postulates that an ontological stance implies a particular epistemological viewpoint and highlights the fact that they are closely related but address different aspects of knowledge and reality. Furthermore, this notion suggests that the ontological notion of realism, which proposes that reality exists outside of the mind (objectivism), is complementary to the epistemological notion of focusing on the validity of knowledge and how knowledge is acquired. Thus, the ontological and epistemological process are mutually dependent and can be difficult to establish conceptually, as the construction of a meaningful reality (ontology) is based on the construction of meaning (epistemology). Table 6 below describes the framework for this study:

Table 6

Study Framework

Criteria	**Paradigm**	**Assumptions/Approach**
Ontology	Realism/objectivism	Reality exists independently. Universal patterns can be used to explain or predict behaviour.

Epistemology	Positivism	Phenomena exists independently. Researcher is independent from subject. Begins with hypothesis and theory (deductive).
Methodology	Quantitative	Generalisable, predictive/ value free/unbiased, statistical
Methods	Cross-Sectional Survey	Variables can be identified, and relationships measured

Ontology: Realism

The ontological position for this study is realism, whereby exploration of the phenomenon will take the epistemological standing of objectivism (Cornish & Gillespie, 2009). Applying the ontological position of objectivism to the examination of illness perceptions among people with dementia and their CGs and the relationship to help seeking assumes that the representation or meaning of a phenomenon has an independent existence. Thus, the data collected (i.e., the survey questions) are assumed to consist of objective facts that represents a reality that already exists in the world, and the role of the researcher is to discover and determine the outcomes.

In the context of this study, the self-regulation model (SRM) (Leventhal & Nerenz, 1985) underlies the understanding of the individual’s capacity to understand their diagnosis of dementia. This in turn influences their experiences, helping an individual to form their own perception of the illness, and the relation of this to their own help seeking. This implies a strong connection to “real world” outcomes, as people living with dementia will seek to understand their diagnosis via their own observations and experiences (Eisenberg et al., 2019). This information is acquired by the researcher via descriptive ideas and informed by language and symbols to describe the phenomenon in real forms as they exist without any interference (Scotland, 2012). Therefore, realism is concerned with the study of being, existence and the nature of reality by exploring the fundamental nature of observed events and how they relate to each other.

Epistemology: Positivism

The word positivism originates from the Latin word "positum" where facts are positioned in front of the researcher (Alvesson,2009). Thus, the objective is to discover the truth of what is observed. To examine these facts, the researcher is required to be objective by using methods that are value free (Scotland, 2012). In relation to the concept of this study, the theoretical framework of the SRM describes a specific relationship to the events, which is explained as a deductive-nomological relationship, as the SRM assumes a universal law that explains the specific event. This approach therefore aims to seek an explanation regarding the role of illness perceptions on an individual's help-seeking intentions once diagnosed with dementia. Thus, the deductive approach applied in this study draws on the theoretical framework of the SRM, by providing a foundation to understand empirical relationships that are predictable in examining the relationship between an individual's illness perceptions and their help seeking once diagnosed with dementia (Stam, 2000).

Positivism focuses on the empirical observation and the use of scientific methods to explain a specific phenomenon. As this study draws on the empirical research of the SRM, and its application of the IPQ-R with people living with dementia the positivist approach was deemed suitable to explain my research aims and objectives. By focusing solely on a quantitative design provided me to compare the different variables of the IPQ-R with help seeking for within and between the person with dementia and the carer. This approach supported my research hypothesis where individuals who reported more strongly held beliefs of dementia would influence their help-seeking intentions.

In choosing this approach, I aimed to place myself in an objective position, thus reducing the possibility of inflicting bias by taking a neutral stance. By acknowledging the objective reality of the illness and providing clear and consistent information for the individual, healthcare services can help identify an individual’s care needs, without being influenced by an individual’s subjective experiences of dementia. Being objective is to apply a realist view of the world, one that is external and independent of human experience (Crotty, 1998). Thus, the existence of reliable knowledge in relation to having a diagnosis of dementia is important to this research, in that it assumes that all that exists are actions or events (living with dementia, and an individual’s perceptions of these events). The evidence provided from these objective measures can inform clinical practice and interventions (Brannan et al., 2017). Hence the hypotheses, which relate to observer-defined variables, are tested to construct discoverable relationships (Bond & Corner, 2001).

This realist/positivist approach is in contrast with the viewpoint of constructivism which proposes that knowledge is not discovered but constructed. Thus, the researcher is to construct an impression of the world as they see it and findings are created as the research proceeds (Ratner,1989). The constructivist position argues that individuals’ actions are not related to the general patterns of human behaviour but are highly complex and dependent on their beliefs, habits, and emotions. Thus, the viewpoint of constructivism cannot be described as objective; however, it cannot be described either totally as subjective as this view rejects the basic existential concept of human beings engaging with their real-life situations (Crotty, 1998).

When dealing with reality, quantitative categories have a theoretical significance only if they involve objective characteristics and real quantities. Thus, by applying quantitative measures it is possible to provide possible explanations for the proposed hypotheses (Creswell, 2008). For this current study, the use of quantitative surveys was used as this approach is concerned with the distribution of a particular trait (illness perceptions and help-seeking) within a specific population (people with dementia and CGs).

Thus, the positivist approach is proposed for this present study, as it examines the dyadic effect on illness perceptions between the person with dementia and their CG and the association with their own help-seeking intentions. Therefore, the positivist approach of adopting an objective viewpoint from the person with dementia and the CG's is important to minimise any possible influences from each member of the dyad. By collecting the data in the form of a validated survey, participant responses cannot be manipulated by others (Stam, 2000). Moreover, the use of surveys based on health behaviour theories such as the SRM assumes that the answers given will disclose pre-existing views rather than answers that have been provoked by the survey (Ogden, 2003).

In consideration of the complex and diverse nature of living with dementia, it could be argued that critical realism (Bhaskar,1978) is implied as an epistemological belief within this study. However critical realism argues that a researcher conceptualises a way of *knowing* that reality, whereas a positivist concept of reality reflects that reality (Bryman, 2016). Critical realism can be seen as a middle ground between positivism and constructivism but alludes to interpretivism/anti-naturalism as well, suggesting a more nuanced stance within a generally realist ontology (Zachariadis et al., 2013). However, the main objective of critical realism is to utilise perceptions of empirical actions and events and to identify the underlying or 'deep' mechanisms involved (Volkoff et al., 2017). Thus, the critical realism view focuses on explaining *causality*, and not the *relationship* among distinct actions or events. However, there could be a presumed causal relationship for this study but cannot be empirically tested. Realism can be positively applied, but it rejects the positivist method, arguing that the real world cannot be observed and exists independently from human perceptions, constructions, or theories. Thus, by applying the positivist approach I can derive that the illness perceptions of people living with dementia is gained from measurable (quantifiable) observations (Bhaskar, 1975).

Therefore, as this study sets out to examine the predictive ability of illness perceptions and their impact on an individual's help seeking intentions, the objective / empirical epistemology standpoint is justified, as examining the effect between illness perceptions and help-seeking means to measure the relationship between variables, not the cause. Moreover, as this approach separates theory from the other components of the research process, it enables the researcher to be unbiased in their approach (Creswell, 2008). Consequently, by examining the relationship between illness perceptions and help-seeking intentions among people living with dementia, the objective of this survey is to determine the strength of the help-seeking intention-behaviour relationship depending on an individual's own perception of their dementia diagnosis within the theoretical framework of the SRM (Suka et al., 2016).

Theoretical framework

Developments in health psychology have utilised the application of health behaviour theories that enable a better understanding of an individual's health-related behaviour (Connor & Norman, 2005). These theories can be divided into two main groups: social cognition models (SCMs) and stage models. The phrase "social cognition" represents beliefs and attitudes directly affecting health behaviours (Sutton, 2002).

Two main types of SCMs that attempt to explain health-related behaviour and response to treatment can be applied to health psychology (Connor,1993). Firstly, attribution models explore causal explanations of an individual's illness (see, e.g., King, 1982). However, most of the research employing this approach has focused on how people respond to serious illness (i.e., cancer, heart disease, diabetes, renal failure) rather than health-enhancing behaviour (Connor & Norman, 2005). The Self-Regulatory Model (SRM) (Leventhal et al., 1984) falls under the category of attribution models, which seek to examine an individual's response to a health threat. In particular, the individual's illness perceptions are seen as the main factor in determining a coping response. The second category examines predictive health-related behaviours and outcomes of the individual, where the individual responds to a health threat and then evaluates their behaviours to counteract the threat (Conner & Norman, 2005). One of the SCMs used to predict health behaviour is the Health Belief Model (HBM) (Rosenstock, 1966), which falls into the second category. However, theories that are specifically applied to examine health-related behaviours that consider an individual's perception of their illness can have noticeable differences (Jones et al., 2014), and thus these two models will be discussed and compared below.

The Health Belief Model (HBM) (Rosenstock, 1966) proposes that the perceived severity of the related consequences to the illness (threat perception) and the perceived susceptibility of the illness along with the action taken (behavioural evaluation) can all contribute to the individual's perception of threat. Perceptions of a threat are interpreted at two key beliefs: perceived susceptibility to an illness and the anticipated consequences of the illness. Behavioural evaluation consists of two specific factors: the benefits of a recommended health behaviour and any barriers in relation to carrying out the behaviour (Connor & Norman, 2005). These two beliefs together impel an individual to take a specific health action. If they believe the illness is serious and they are susceptible to the illness, they will believe the actions they take will be of benefit to them. Thus, high beliefs in the severity of an illness, a susceptibility to it and the benefits of particular behaviours, and low beliefs in barriers to the illness suggest that the individual will adopt the recommend behaviour (Sutton, 2001).

In contrast, the Self-Regulatory Model (SRM) (Leventhal & Nerenz, 1985) provides a framework describing how emotions and individual symptoms experienced during a diagnosis or health threat influence an individual's perception of their illness and subsequent coping behaviour. In Leventhal's (1997) model of stress and coping, how an individual perceives their illness (cognitive illness representations) and their emotional reactions to a specific health problem form the model. The cognitive component consists of five categories of subjective beliefs: Identity-perceptions of symptoms, cause, perceived cause of the illness, perceptions of the timeline course of the illness (acute or chronic), perceptions of the controllability of the illness and its consequences, and the perceived impact of controlling the illness (Moss-Morris et al., 2002).

It has been argued that substantial overlap exists between the two models, but with some important differences. For example, the HBM considers that beliefs about recommended behaviour formed by the individual determine an individual's behaviour. However, this has been criticised as being too static (Connor & Norman, 2005). In contrast, the SRM focuses on the illness beliefs of the individual in a more dynamic fashion, suggesting that an individual's own health behaviours are influenced by their own changing beliefs of the illness in terms of coping mechanisms, illness threat and consequences (Connor, 1993). To understanding an individual's motivational behavioural process, a dynamic self-regulatory approach is needed to explain how individuals allocates cognitive and affective resources across various tasks (Lord et al; 2010). Furthermore, the HBM does not relate to a particular illness, whereas the SRM can be adapted to specific illnesses (Shinman-Altman & Werner, 2017). Moreover, the SRM addresses the role of emotion in decision-making, whereas the HBM does not, and it also provides a more in-depth construction of perceived severity (Sutton, 2001).

Nonetheless, the SRM is not without weaknesses and has been commented on for not including a more robust description of the barriers and benefits factors that are associated with health-related decision-making (Jones et al., 2014). Therefore, considering the differences between the HBM and SRM models, it was considered that the SRM offers a more suitable model for this piece of research, as it considers the illness belief-behaviour relationship and emotional factors, and can also be adapted for use among people living with dementia (Roden, 2004). The SRM has a significant emphasis on self-regulation and coping processes such as help-seeking. It explores how individuals actively adjust their beliefs, emotions, and behaviours in response to a health threat, whereas the HBM does not explicitly emphasise self-regulation as a central concept. Therefore, the SRM is considered as a conceptual alternative to the HBM when considering the coping and adaptive strategies of people living with dementia (Matchwick et al., 2014).

There are examples of studies applying the SRM as a theory to explain illness perceptions in individuals with dementia (e.g., Clare et al.,2006; Harmen & Clare 2006; Hamilton West et al., 2010). These studies have been shown to be useful in helping explore certain cognitive factors in relation to perceptions of dementia and an understanding of the individual’s condition. For example, Hamilton – West et al.’s (2010) study applied the common-sense model of self-regulation of illness representations (CSM) (Leventhal et al.,1980) to understand people’s lay perceptions of dementia and their association with help seeking intentions. The CSM uses the same key constructs as the SRM and is in essence the same theoretical framework for conducting research examining illness perceptions within a range of health conditions (Hale et al.,2007). That is, the CSM posits that illness perceptions guide an individual to seek help to control the illness threat, thus providing a dynamic model associated with adapting to living with an illness (Chilcot et al., 2012). Findings from Hamilton-West et al.’s (2010) study revealed that cognitive problems were associated with dementia, rather than non-cognitive symptoms, which were attributed to depression or stress. Furthermore, the study indicated that people were more likely to seek help if they perceived symptoms as severe, and had serious consequences, but less likely to seek help if they attributed symptoms to psychological issues.

Moreover, Clare (2003) describes the development of illness perceptions as a process of developing awareness; however, the ability to detect dementia may be compromised due to the cognitive deficits experienced by the person with dementia. Lack of awareness can have implications for the CG, also, and has been linked to greater perceived CG strain (Clare, 2003). Considering this phenomenon of an individual’s understanding of their dementia, two studies were conducted (Harman & Clare, 2006; Clare et al., 2006) to explore how people with a diagnosis of early-stage dementia make sense of their diagnosis and how this affects their ability to cope and adjust. Utilising the SRM, the findings indicated that illness representations informed by the SRM can help develop an understanding of people’s ability to manage the threat to self and their coping strategies when living with dementia.

Chapter 4: Methods

The following section describes recruitment strategies and the identification of the sample. Also, data collection methods, analysis design and statistical framework applied will be described, as well as ethical considerations for conducting research with people living with dementia.

Sampling and Recruitment

Recruitment strategy: The researcher utilised convenience sampling and was able to access a pre-existing research database of research volunteers through her role as an NHS senior clinical researcher. This database is an approved dementia research register of people who have already given their consent for researchers at Surrey & Borders Partnership Foundation NHS Trust (SABP FT) to access their medical records for research purposes. The researcher is trained in Good Clinical Practice (GCP) and is fully trained in informed consent procedures involving research participants living with dementia. (See consent forms in Appendices 2 & 3).

The researcher pre-screened prospective participants, utilising a pre-defined inclusion criterion, outlined by the study eligibility criteria (see Table 7). The researcher was the sole person to identify potential participants. The role of the researcher at their place of work is that of a senior researcher for various research projects (adult mental health & dementia), and for the purposes of this study, my role was defined as study coordinator and recruiter. Full NHS ethical approval (REC ref;18/ES/0068) for this procedure was gained before recruitment commenced (see Appendix 1 for all approvals).

Potential participants were also identified at Surrey & Borders Partnership Foundation Trust (SABP FT) community mental health recovery services for older people (CMHRS OP), via a network of contacts (care coordinators, specialist clinicians). Research leaflets and information sheets were sent to nine SABP FT CMHRS OP clinics by post or email. Also, expression of interest leaflets was left in memory clinics. Those who expressed an interest in participating in the study were asked to sign a consent to contact form.

Once a person with dementia and their caregiver (CG) had been identified as being eligible, the researcher contacted them by phone, when they had the opportunity to ask further questions about the study. Thereafter, the researcher arranged a convenient time and place to meet with participants. During this visit, the researcher assessed the capacity to consent for the person with dementia and their CG and explained the study to them and what their involvement would entail. Once the person with dementia and the CG agreed to take part, they both signed a consent form before any questionnaires were completed. Participants were seen at home and in clinic settings, and any participants who declined to take part were thanked for their time and reassured that not taking part would not affect their standard of care in any way.

Eligibility Criteria

Table 7 outlines inclusion criteria for the person with dementia and the CG.

Table 7

Eligibility Criteria for Dyads (Person with Dementia and Caregiver)

Person with Dementia Inclusion Criteria	**Caregiver Inclusion Criteria**
• Alzheimer's disease (AD), vascular dementia (VD) (including mixed dementia of AD and VD), frontal temporal dementia and Lewy body dementia (confirmed by SABP Consultant Psychiatrist for older adults). • Male or female adults >18 years.	• Informal caregivers of PWD to provide support > 4hrs a day and to be aged >18. • All participants need to have sufficient understanding of the English language and all carers to be directly involved with the patient's care. • Have capacity to provide informed consent.

• Mild stage dementia; Mini Mental State Examination (MMSE) >23 (Folstein et al.,1975) or equivalent to the Addenbrookes Cognitive Examination (ACE III) (Mathuranath et al., 2000). • Living in the community. • Receiving >4hrs per week of home care from the caregiver. • Has nominated an informal carer. • Has sufficient understanding of the English language. • Has capacity to provide informed consent.	

Sample size

An *a priori* power calculation indicated that 84 dyads (person with dementia and CG) would enable the study to have 0.8 power, with an alpha level of 0.05, allowing the anticipation of a medium effect size when predicting help-seeking intentions in relation to an individual's own illness perceptions. Kenny, et al. (2006) conducted a survey of 78 studies and examined a subset (*n* = 25) that measured both members of the dyad using a standard design. The number of dyads ranged from 25 to 411, with the median number across all 25 studies being 101. According to Kenny et al. (2006), a typical sample size for this type of study is around 80 dyads.

However, our original number of 84 dyads was not obtained due to COVID-19 restrictions and, as a result of these restrictions which made home visiting impossible, recruitment was halted in April 2020. Consequently, a final sample of *n* = 56 dyads was recruited between September 2018 to March 2020.

To allow for a dyadic analysis scores of individuals' unit measures were retained; however, these were treated as nested within the dyad as "this approach allows for estimation of both individual and dyadic factors" (Cook & Kenny, 2005, p.102). Thus, the nested ratio effect was used, allowing for a ratio of 10:1 between subject and variable (i.e., at most, 10 subjects per predictor). Therefore, our sample size of 56 would allow as many as 5 predictors in each model (Kenny et al., 2006).

Data Collection

Once the participants had read the patient information sheet and had been given the opportunity to ask further questions, they were asked to sign a consent form. Moreover, both the person with dementia and CG needed to agree to take part in the study. Since participants with dementia may have varying degrees of cognitive impairment, it is essential to assess their capacity to provide informed consent. To assess this, I went through the patient information sheet and consent form with both the person with dementia and CG. I asked them to relay back to me that they understood the purpose and nature of the study, including any potential benefits and risks associated with the study. I allowed the participants adequate time to retain the information so they could make an effective decision without any coercion from myself.

Data were collected with participants at the local clinic (*n* = 7), or at the participant's home (*n* = 49) after a suitable time had been arranged. Questionnaires incorporated demographics of social and personal characteristics and psychological self-report tools that measured illness perceptions, anxiety and depression, quality of life, plus help-seeking (see Appendices 4 & 5 for survey questions). Questionnaires were self-administered; however, the researcher (who was present during data collection) offered support in completion of questionnaires to both the person with dementia and the CG if needed. Initially, it was suggested that the survey could be completed online or by post. However, on consideration of the mutual influences that could arise between the dyads' individual responses, it was considered more appropriate for the researcher to be present at the time of the survey completion. Moreover, with the researcher present, participants were able to ask any queries and missing data were minimised. Completion of the survey took 45 to 60 mins for each member of the dyad (the person with dementia and the CG). Once the data were collected, it was inputted into the statistical software package, SPSS v.26 (Statistical Package for the Social Sciences).

Measures

To examine illness perceptions and their impact on an individual's help-seeking intentions, the following questionnaires were used:

Primary Outcome: General Help-Seeking Scale (GHSQ) (Wilson et al., 2005)

The GHSQ was utilised to assess the help-seeking intentions of the person with dementia and their CG. The GHSQ provides a sensitive and flexible format for measuring help-seeking intentions that are not necessarily specific to dementia and provides a suitable format for clinical practice, prevention initiatives and mental health promotion (Wilson et al., 2005). The GHSQ is a self-report scale comprising 20 items with a five -point Likert -type response format of "extremely likely" to "extremely unlikely". Higher scores equate to a person being more likely to seek help, with a potential score ranging from 8 to 56 (Cronbach's alpha = .85, test-retest reliability =.92) (Wilson et al., 2005).

There is no specific scale examining help-seeking for dementia. Thus, we applied the GHSQ as it examined the probability that the person with dementia and CGs would seek help from significant others, health professionals and dementia charities. Moreover, the GHSQ has demonstrated positive associations with retrospective and prospective help-seeking behaviour and aspects of emotional competence in individuals with signs of dementia (Phillipson et al., 2015).

In respect of validity, correlations between intentions and actual help-seeking behaviours have been reported as moderate for "several informal sources (e.g., *rs* (181) = .48, p < .001, intimate partner; *rs*

(218) = .42, p < .001, non-parent family)" (Wilson et al., 2005, p.24). Scoring of the GHSQ can be as a single scale, including all specific help seeking options, or as two subscales, one each for problem type (personal/emotional and suicidal problems). For this study, the GHSQ will be scored as a single scale so that all specific help seeking options can be analysed.

Predictor Variables

Illness Perception Questionnaire Revised (IPQ -R) (Moss-Morris et al., 2002)

The IPQ (Weinman et al., 1996) was originally devised to measure the dimensions of the Self-Regulatory Model (SRM) (Leventhal et al., 1980, 1997). It was later revised (IPQ-R: Moss-Morris et al., 2002) to include illness coherence and emotional representation. The IPQ-R is a self-report measure and consists of nine subscales. The nine subscales of the questionnaire consist of *identity* (14 items), *timeline acute and chronic* (10 items), *consequences* (6 items*), control and cure* (11 items), *emotional representation* (6 items*) coherence* (5 items) and *cause* (18 items) and comprises three parts.

The first part measures the identity component with a list of the most commonly occurring general symptoms identified by the IPQ-R. Most of the dimensions of the IPQ-R can be applied generically across various conditions; however, identity and cause subscales can be modified to fit specific conditions (Simpson et al., 2013). Therefore, the identity and cause components in this study comprised original scale items plus dementia-specific symptoms (for the identity subscale) and causal attribution of dementia (for the causal subscales). For this study, after consultation with dementia specialists in mental health for older people, the identity and cause subscales of the IPQ-R incorporated items relevant to having a diagnosis of dementia. The identity dimension was supplemented by seven additional items, with a removal of the sore eyes item, thus resulting in a 20-item scale. The seven additional items were agitation, anxiety, loss of movement, hallucinations, delusions, memory loss, and aggression. Using a yes/no response, participants noted whether they experienced specific symptoms, and whether they believed the symptoms, were related to dementia. The causal attributions dimension used the same five-point Likert scales. Four extra causal attributes related to dementia - brain injury, diabetes, obesity, and gender - were added to the causal dimension resulting in a 22-item scale.

The remaining seven subscales consist of 46 items, and participants responded using five-point Likert scales (strongly agree to strongly disagree), in relation to their illness perceptions of timeline, control, coherence, consequences, and emotion in connection to having dementia. High scores on the identity, timeline acute or chronic and consequences domains represent more strongly held illness perceptions about dementia. High scores on the personal control, treatment control, timeline acute and chronic, emotional representations and coherence domains represent more stronger illness perceptions about the controllability of dementia, and a personal understanding of the illness. The interpretation of a high score for the IPQ-R depends on the specific dimension being measured. In respect of illness identity, a high score indicates that individuals perceive their symptoms of dementia as having a significant impact on their daily life. High scores of the timeline subscale indicates that individuals may perceive their dementia as chronic, with high scores of the consequences subscale suggesting that individuals perceive their dementia as having severe consequences, posing a significant threat to their quality of life. A high score on emotional representations suggests that individuals experience strong emotional responses related to their dementia. Higher scores on treatment and personal control, plus illness coherence, represents a more positive control over dementia (i.e., control over the illness) (Sterzo & Orgeta, 2017). Assessment of help-seeking intentions is the dependent variable, with scores of the IPQ-R dimensions applied as the potential predictor variables. Regarding confounding variables, MLM will enable an adjusted comparison, provided assumptions are made about how anxiety, depression and quality of life affect an individual’s help-seeking behaviour related to their own illness perceptions (McNamee, 2005).

As dementia is a complex and chronic condition it was deemed more appropriate to use the IPQ-R more than the Brief Illness Perception Questionnaire (BPIQ, Broadbent et al., 2006). The IPQ-R lends itself to offer a more robust analysis of an individual's illness perceptions. By applying the IPQ-R we were able to examine the specific correlations between an individuals' illness perceptions and help-seeking. In contrast, even though main advantage of the BPIQ is its simplicity, it is a single item scale. A single item scale was not considered adequate enough to capture the content of each of the IPR-R's dimensions concisely (Broadbent 2015).

In general, the dimensions of the IPQ-R have shown good reliability with test-retest reliability showing good stability; displaying medium to high effects with Pearson's correlations of 0.46- 0.88 (Moss-Morris et al., 2002). Moreover, the IPQ-R has been successfully adapted to measure spouses' beliefs about a loved one's illness ((Moss- Morris et al., 2002). In respect of CGs, the questionnaire replaced the word '*illness's* with '*your relative's/friend's illness'.* Cronbach's alpha for the IPQ – R subscales showed good reliability with a range from 0.821 to 0.903 within a sample of people with Mild Cognitive Impairment (MCI) and their CGs (Lingler et al., 2016).

Hospital Anxiety & Depression Scale (HADS)

To measure anxiety and depressive symptoms, the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) was utilised. The HADS is a widely used self-report measure, originally designed to assess anxiety and depressive symptoms among hospital outpatient populations but also used within elderly patients with early-stage dementia (Spinhoven et al., 1997; Ostojic et al., 2014.) The HADS has two separate subscales (anxiety and depression) and is appropriate in clinical and non-clinical populations of older adults and has been validated as scale to identify clinically significant depression and anxiety (Mykletun, Stordal, & Dahl, 2001). A Cronbach's alpha of 0.85 has been reported for depression in the HADS, and 0.83 for anxiety in CGs of people with dementia (Sterzo & Orgeta, 2017). The HADS has seven items in each subscale, and for both scales scores that are <7 indicate non-cases of depression & anxiety, 8-10 = mild cases, 11-14 = moderate and 15-21 = severe.

European Quality of Life- Five Dimensions (EQ-5D) 5 level. Available at https://euroqol.org/eq-5d-instruments/

To measure an individual's health related quality of life, the EQ-5D was applied. The EQ-5D provides a simple self-report descriptive portrait of an individual's quality of life and reports a single index value for the individual's health status at time of completion (Herdman et al., 2011). The questionnaire includes five dimensions of - mobility, self-care, usual activities, pain/discomfort & anxiety/depression - with higher scores indicating more severe problems. It also includes a self-rated health status derived from a visual analogue scale (VAS) with 0 correlating to worst imaginable health, and 100 correlating to best imaginable health.

The EQ-5D is widely used among clinical and economic evaluations because of its good validity, high reliability, short completion time, and responsiveness (Hounsome et al., 2011). The EQ-5D has shown acceptable reliability; for example, in a study that applied the EQ-5D among people with dementia test-retest reliability reported ICC = 0.74, p= .001 (Ankri et al., 2003). Also, Luo et al. (2011) reported Cohen's k being moderate to good applying the EQ-5D to patients with rheumatic pain with 21-0.40 for pain and discomfort dimensions and 0.41 – 0.80 for usual activities.

Analysis Plan

As this study is exploring illness perceptions and help-seeking intentions among two individual groups (the person with dementia and the CG), analysis will be within a dyadic format. As caregiving is an extension of caring for a loved one and caregiving is embedded in most close relationships, the concept of dyadic analysis is intrinsic in the examination of illness perceptions of people living with dementia (Pearlin et al., 1990). Consistent with this approach, Berscheid (1999) observed that relationships between individuals are like ‘great forces of nature’ in that they are powerful but ultimately invisible. By observing the effects of this relationship, it is possible to gather knowledge of their qualities and character (Campbell & Stanton, 2015). Thus, the dyadic measurement of two individuals will reflect the contributions of the two individuals; however, the function of each response may be different (Bond & Kenny, 2002).

To examine this effect, the Actor Partner Interdependence Model (APIM) framework for distinguishable dyads was utilised (Kenny et al., 2006). This model can be used for dyads that have distinguishable members or for dyads that are non-distinguishable. A distinguishable dyad can be considered if there is a meaningful factor that can be used to order the scores of the two individuals and that can be differentiated on a within-dyad variable. Examples of distinguishable dyads are husband and wife, parent and child and teacher and student. In contrast, members of an indistinguishable dyad cannot be meaningfully distinguished by a variable, and there is no systematic way to order the two scores; examples of indistinguishable dyads are twins, work colleagues and acquaintances (Kenny et al., 2006).

Specifically, the APIM approach allows for researchers to estimate effects simultaneously. It indicates whether an individual independent variable score has an effect on both their own dependent variable (known as the actor effect) and their partner’s dependent variable score (known as the partner effect). In statistical models that are used to estimate the actor and partner effects, the dyad, not the individual, is used as the unit of analysis. The model has been recommended for use in the study of close relationships (Campbell & Kashy. 2002) and in the study of families (Raynes & Svavardottir, 2003).

Dyadic Design

The study of dyads refers to the study of a dyad as the unit of analysis using a regression model with the dyadic measurements as the outcome variable. The relation between the two members can be undirected or directed. Directed implies relations between dyads that may not necessarily be mutual; an example of a directed relation is friends, as friendships are not necessarily reciprocated. In contrast, undirected relations are those that are reciprocal in some shape or form; an example of undirected relations are marriages (Kenny et al., 2006). A main feature of the dyadic design is that the dyadic outcomes observed are not applied to explain the relationship with each other but the direction of the observations (Cranmer & Desmaris, 2016). For example, the cross-level approach in dyadic analyses has largely focused on observed dyad level variables (i.e., length of relationship) as predictors of individual-level outcomes (e.g., relationship satisfaction) (Wickham & Macia, 2019).

There are three types of predictor variables within dyad research: within dyads, between dyads and mixed variables. A within dyads variable is when each score for partners within the dyad is different, but the average score for all dyads is the same. On the other hand, the between-dyads variable is where scores are the same for both members of the dyad, but they differ across dyads. In the case of this study for within dyads, the scores of the person with dementia and the CG for the effect of their own illness perceptions on their own help seeking will be different, but the sum of scores for the person with dementia and the CG will be the same for every dyad. However, regarding between dyads, the scores of the person with dementia and the CG for the effect of their own illness perceptions on their own help-seeking intentions will be the same, and both the person with dementia and the CG will have the same scores (Kenny et al., 2006).

Regarding mixed predictor variables, there is variation both between and within dyads. Thus, to answer the research question, mixed variables will be utilised as people will score higher or lower than other members on each variable of the IPQ-R, as well as the average score of each variable differing within and across dyads. Understanding how the dyad level components of individual variables may predict either the individual or dyad level variable components has the potential to provide a more robust and inclusive analysis of the dyadic relationship.

As discussed, earlier, most studies that use a dyadic design can be considered to be violating the independence assumption, in that observations from the data set are independent and are not related to or affected by each other in any way. Therefore, analysis of dyadic data can be described as non-independent, as two members of a dyad are not just two independent individuals but can share a common experience (Fitzpatrick et al., 2016).

Dyadic Analysis in the Context of Living with Dementia

Living with dementia and dealing with the day-to-day demands of caring for a loved one with dementia involve reciprocal dyadic coping (Hausler et al., 2016). Reciprocal coping within dyads can be described as an exchange between dyads with similar behaviours and may reflect complementarity or compensational ties (Kenny et al.,2006). The provision of informal care by CGs for a person with dementia can be physically and mentally distressing (Gellert et al., 2018) and informal CGs can develop anxiety and depression due to the strain associated with their caregiving duties (Lester et al., 2022). To reduce the burden for both partners, coping strategies and a mutual understanding are required (Revenson et al., 2016).

Seeking help within the dyadic relationship is especially relevant to people living with dementia, as poor or inadequate coping on the part of the CG may shield the person with dementia as well as the CG from negative physical and mental consequences. A delay in help-seeking can limit input from healthcare systems able to provide support for the person with dementia (Martin et al., 2009). Moreover, better caregiving can help maintain a good relationship between both partners, despite the progressive decline of the disease (Revenson et al., 2016). How each partner perceives seeking help, once having received a diagnosis of dementia, can be interrelated with their partner’s own perceptions; that is, each partner is likely to affect the other’s illness perceptions of help seeking.

A review by Braun et al. (2009) evaluated research studies that concentrated on the impact of dementia on the spousal dyad, with its main aim being to evaluate how many studies integrated a dyadic perspective. The review reported that very few studies embraced the dyadic perspective of living and caring for someone with dementia. By ignoring the dyadic perspective, the review highlighted the importance of examining this phenomenon and its impact on an individual's ability to cope with living with dementia (regarding the person with dementia and the CG). Thus, from a dyadic perspective, the increasing loss of individual autonomy can be related to the progression of the disease, resulting in ongoing changing needs and support from the CG to maintain dyadic independence (Martin et al. 2009).

As the onset of dementia progresses, the exchange, and the act of assisting with daily tasks becomes unbalanced and asymmetrical; however, these experiences are not all negative. A study by Heru (2004) examined spousal CGs of people with moderate dementia and reported that CGs perceived their responsibilities as more rewarding than burdensome, suggesting that CGs may perceive caring as satisfying and fulfilling, even if they still experience relationship problems, (e.g., negative responses from their partners). Additionally, a longitudinal study of people living with dementia demonstrated that CGs who reported having better coping strategies were associated with slower cognitive decline of the person with dementia, suggesting that a CG's own coping strategy could predict memory decline of the person they care for (Tschanz et al., 2013). Moreover, a growing consensus suggests that individual coping is related to better health outcomes when patient and CG are both involved in the care pathway (Gellert et al., 2018). For example, a study by Revenson et al. (2016) proposed that married couple's reciprocal influences of anxiety and depression were related to each other's own mental health and disrupted sleep patterns. This suggests that sleep problems might be better managed as a dyad level phenomenon than as an individual one.

Thus, dyadic analysis is of importance, as focusing on the dyadic relationship can help develop better therapeutic interventions and support for both the person with dementia and the CG.

Actor Partner Independence Model (APIM) for Dyadic Analysis

Research in the behavioural and social sciences has often discussed the limitations of using the individual as a unit of analysis (Fitzpatrick et al., 2016). In the past, the main reason for this individualistic approach has been that most quantitative social science research in the field of psychology has emphasised the analysis of the individual (Cook & Kenny, 2005). However, applying this approach does not consider the mutual influence of the social interactions we have in close relationships with family and friends. More pertinently, by ignoring the family as a network of relationships connected by social interactions, and usually dyadic in nature, theoretical understanding of the dyadic relationship is undermined (Schrodt, 2015). Schrodt (2015) also highlights the issue of the independence assumption, and how this has distracted researchers from dyadic analysis. Thus, to analyse dyadic data, a major concept is that of non-independence. Hence, research into dyads presents an opportunity to investigate the mutual influences that partners have on each other in respect of their own individual health and wellbeing (Revenson & DeLongis, 2011). Consequently, the aim of this study is to examine the effect of the dyadic relationship on the illness perceptions of the person with dementia and the CG and their own help-seeking intentions by utilising the APIM.

The APIM is being increasingly applied in health and social science research and has been recommended in family studies (e.g., Nagpal et al., 2015, Lingler et al., 2016). The APIM has been growing in popularity over the past years and can be seen as a useful tool for analysing data that is nested within higher level orders within the components of dyadic design (Hong & Kim, 2019). Within the field of dementia research, applying the APIM as an analytic approach has been increasing over the years. For example, Gellert et al., (2017) examined the association between own dyadic coping and perceived dyadic coping with depressive symptoms in couples coping with dementia. Moreover Moon et al., (2017) investigated incongruence in people with dementia and their carer’s perceptions of the person with dementia involvement with decision making and the effect on their quality of life. Both studies demonstrated the importance to include both the carer and the person with dementia views of their own illness perceptions of dementia individually as well as couple, thus informing future interventions that target the dyadic relationship.

The APIM Statistical Model Framework

The APIM is a statistical model of relationships between dyads. It incorporates a conceptual view of interdependence in a two-person relationship (Kenny et al., 2006). The APIM can estimate the degree to which the independent variable of an individual influences his or her scores on the dependent variable ($X1 \rightarrow Y1$), with the actor effect denoted as a. It also estimates the degree to which the independent variable influences the dependent variable of his or her partner ($X1 \rightarrow Y2$), with the partner effect denoted as p. Therefore, the effect that a person's independent variable score has on their own dependent variable score (actor effect), and on their partner's dependent variable score, contributes to the variation across the data (Kenny, Kashy, & Cook, 2006). When the assumption of independence is violated, the test statistic (F or t) and the degree of freedom are incorrect, the test can be statistically significant (p-value) but biased. For example, in our study, understanding how the person with dementia and their CG as a dyad perceive and respond to a diagnosis of dementia is important because illness perceptions of dementia may influence how the affected dyad seeks out help. Thus, illness perceptions of dementia among dyads would be associated with their own as well as the other member of the dyad response to ask for support. Thus, the scores of the two linked people would be treated as if they were completely independent observations, when in fact, the correlation would show that they are not independent.

The APIM model provides a platform to help identify a variety of theoretically meaningful dyadic patterns. Four types of patterns have been proposed by Kenny and Cook (1999). In order to identify a pattern, a ratio is computed with the actor and partner effect that can be regressed to the same outcome (i.e., $Y1$ or $Y2$). The first pattern is the couple pattern and is represented by $a = p$, with this pattern considering the actor and partner effect as equal. The second pattern is the contrast pattern and is represented by $a + p = 0$; it considers the effect that the actor has on their own outcome is the opposite of the effect the partner has on the actor's outcome. The third pattern is the actor-only pattern and is represented by $a \neq 0$, $p = 0$; in this case, there are actor effects, but no partner effects. The fourth pattern, which is the rarest, is the partner-only pattern and is denoted by $a = 0$, $p \neq 0$; in this model a person is affected by their partner's score on X but not affected by their own X score.

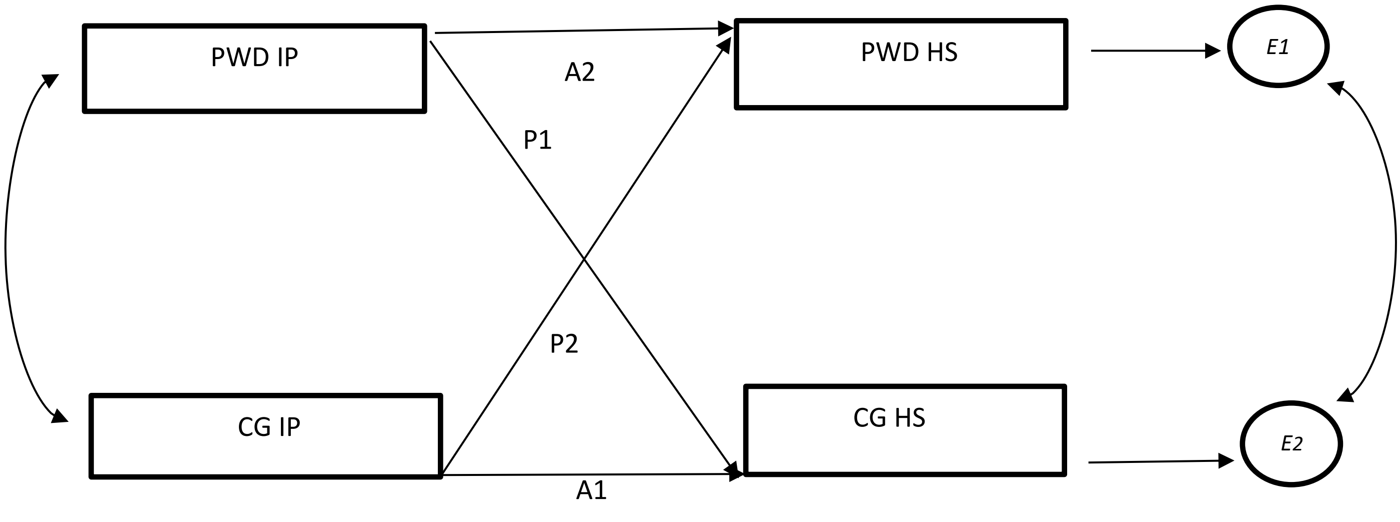
Kenny et al. (2006) assert that it is necessary to estimate partner effects to show that they are zero. If the partner effects were underestimated, the estimated actor effects would be biased, in the partner-only pattern, in that each member of the dyad would only be influencing the outcome of their partners but would not be affected by their own outcome. However, if the actor effects are ignored, then the partner effects may be estimated. According to Kenny et al. (2006), even if the partner effects are of principal importance, controlling for actor effects is still required. Normally the actor effects and partner effects can be tested at the same time, and mutually controlled, as both effects can be significantly biased (Orth, 2013). A robust analysis of the size of actor and partner effects is important, as partner effects are essential from the theoretical perspective of the APIM (Dryenforth et al., 2010). Moreover, the impact of shared variance on the APIM estimates is important as the model is regularly used in many areas of research (e.g., cognition, health, attachment & communication) (Orth, 2013).

Within the context of this study, an example of the couple pattern model where actor and partner effects are equal is when the person with dementia is affected as much by their own illness perceptions as by their CG's illness perceptions with regard to seeking help. This pattern would occur if the person with dementia were as concerned with the CG's behaviour as their own behaviour (help seeking). This type of orientation can be characteristic of shared living (Clarke & Mills, 1979).

As this study focuses on the dyads’ (the person with dementia and their caregiver) illness perceptions and the association with help-seeking, the person with dementia (*X2 → Y1*) or the CG with the partner effect is denoted as *p*. Thus, the effect of the illness perceptions of the person with dementia on their help-seeking intentions is called the actor effect, and the effect of their illness perceptions on their CGs help-seeking intentions is called the partner effect. For the purposes of this study, dyads will be classed as distinguishable (defined by their role within the dyad, either as the person with dementia or the CG). If dyad members are distinguishable, there are two actor effects (one for person 1 and one for person 2) and two partner effects (one from person 1 to person 2, and one from person 2 to person 1). Figure 3 portrays the model, with actor effects represented as *a* and partner effects represented as *p*. The two correlations are represented by the curved lines (the illness perceptions of the person with dementia and of the CG on the left, and the outcome scores *E1* and *E2* on the right.

Figure 3

Actor Partnership Independence Model (APIM) Variables. Actor refers to pathways where the predictor and outcome models have been measured (a). Partner effects refer to pathways across partners (p). Curved arrows refer to correlated predictors.



Note: PWD = person with dementia, CG = Caregiver, IP= Illness Perceptions, a= actor, p = partner, IP= Illness perceptions, HS= Help-Seeking.

A1 = Actor effect of the CG's own IP on the CG's HS.
A2 = Actor effect of the PWD own IP on the PWD HS.
P1 = Partner effect of PWD own IP on the CG's HS.
P2 = Partner effect of the CG's own IP on the PWD HS.

Multi-Level-Modelling (MLM)

To address the measurement challenges inherent in the APIM statistical model framework discussed in the above section, two methods are advocated for the analysis of dyadic data: Structural Equation Modelling (SEM) (Kline, 2011) and Multi-Level Modelling (MLM) (Tabachnick & Fidell, 2007). These models consider the scores of each person within the dyad relationship. Essentially, this is the same as analysing data at group level (Fitzpatrick, 2016).

Estimating the APIM with SEM can be a challenge as it does not allow for analysis of mixed variables (variation between and within dyads) and usually requires a larger sample size for the APIM than the MLM does (Hong & Kim, 2019). With mixed variables, there is variation both within and between dyads within this study as the IPQ-R items display continuous variables. The outcome measure of help seeking is classed as mixed variables as some individuals can score lower or higher than others on each variable, and the average level of each variable within a dyad differs across dyads. This is in contrast with between- and within-dyad variables, where between-dyad variables show that both members of the dyad have the same score, and the within-dyad variable is when the sum of the two individual scores is the same for every dyad (Cook & Kenny, 2005). Also, actor and partner effects can be directly estimated for mixed variables, but not for within- or between-dyad variables (Campbell & Stanton, 2015).

As the APIM can be applied with smaller sample sizes and considers that mixed predictor variables can vary both within and between variables, this model can contribute to the analysis of variation within mixed variables (Kenny et al.,2006). Moreover, the APIM can be seen as a multi-level model as it allows for similarities across members of the same group. Also, the structure of multi-level data incorporates each group of a pair of couples (person with dementia and CG). Thus, for this study, the analytic approach taken was Multi-level Modelling (MLM).

MLM considers social contexts as well as individual respondents, as data that are nested in structure can violate the assumption of independence; this is a requirement of multiple regression analyses (Kirwan et al., 2013) and takes on the measurement of non-independence (sharing something in common). The MLM was applied as it can simultaneously model each dyad outcome while still controlling and estimating the degree of shared variance within the dyad (Miller et al., 2019). Thus, MLM techniques were utilised to examine whether illness perceptions predict help-seeking intentions after controlling for anxiety, depression, and quality of life, using a two - level MLM approach, where individual observations are nested in dyads. Thus, the estimation of the MLM within this current study has two steps. The first step is an analysis of each upper-level unit, which is the dyad; thus, the analysis computed for each dyad examines the relationship between illness perceptions and help-seeking. The second step is the results of the first step analysis disaggregated across the upper-level units (dyads).

Data Preparation and Analysis

Data were organised as mixed independent variables as there is a tendency for individual-level scores (dyads may have the same or different scores) (Kenny et al., 2006). Identification of the variable for dyads was made by combining two individuals to form a dyad ID number (i.e., 001,002), so scores could be linked to that particular dyad. Simple coding (comparing each level of a variable to a reference level) of categorical data was applied so that each level of categorical level can be compared to the lowest or any given level. Missing data was coded as 999. Pairwise structure was applied so that 'scores are a combination of the individual and dyad, with the aim being there is one record for each individual, but that both scores can occur on each record as well. Thus, data were entered twice each for one individual score on variables, as well as the other individual scores on each variable. For example, the variable scores of the person with dementia were entered under dyad ID 001, then CG variable scores were entered under dyad ID 001. In SPSS (V.26), a separate brief file was created by selecting variables that displayed positive correlations with the GHSQ. Thereafter, this file was used to create a pairwise dyad database by utilising Kenny's (2015) software programme for estimating the Actor Partnership Independence Model for Multilevel Modelling (APIM_MM).

Prior to modelling, that is, to applying an MLM analysis, study data were verified to assess whether MLM was suitable; this verification was accomplished by examining the Intra-Class Correlation (ICC). ICC estimates and their 95% confidence intervals were calculated based on a 2-way mixed effects model. The ICC reflects the proportion of the total variability of the outcome that is attributed to groupings (Kirwan et al; 2013). If most of the variance in the dependent variable (help-seeking intentions) is within-group, then groups will not vary on the dependent variable, suggesting that Level 2 units are not that different from each other and that it would not be necessary to examine Level 2 predictors (i.e., nested within groups) (Kahn, 2011). To define a final list of predictors when utilising MLM analysis, an exploratory analysis was conducted to evaluate how certain predictors correlated with each other and with the dependent variable. By doing this, it was possible to identify the most relevant dimensions of the IPQ-R, to avoid building multiple models that could inflate the possibility of having type 1 errors. Predictors (IPQ-R scale items) were grand – mean centred, using the mean of the combined data, as recommended by Campbell and Kashy (2002).

Exploratory Analysis

The researcher familiarised herself with the data and checked for inconsistences to create a clean data set. This process consisted of checking variable scores that could be out of range because of syntax problems and amending as appropriate. Tests of normality of distribution were assessed by the Kolmogorov-Smirnov statistic and was supported by a normal Q-Q plot. Scatter plots were conducted to check for outliers and linearity. Demographic characteristics collected consisted of age, gender, ethnicity, employment status, education level, and relationship status, type of dementia, early or late onset of dementia, family history of dementia and comorbidity of physical illness. Descriptive statistics (e.g., means and standard deviations) were calculated for all variables including the demographic and clinical characteristics of the person with dementia and the CG. This aided in checking for distribution and symmetry of scores on all continuous variables and for frequency distribution in categorical variables. The characteristics of the sample were summarised in terms of frequency for categorical variables, and continuous variables were summarised as mean and *SD*. Independent t-tests for continuous variables, and X^2 tests for categorical variables were used to examine differences in parameters between people with dementia and their CGs. The categorical variables of employment and education were re-coded into two different groups to produce a X^2 2x 2 table. Employment was recoded into working and non-working, and education into school age education and higher education.

To define the final list of predictors when utilising the MLM analysis, an exploratory analysis was conducted (supported by theory) to evaluate how certain predictors correlated with each other and with the dependent variable. The analysis investigated mixed independent variables, as mixed independent variables allow issues of mutual influences to be explored (Kenny et al, 2006). Next, a factor analysis was conducted of the IPQ-R cause subscale, as recommended by Hagger and Orbell (2004), so as to identify groups of causal beliefs. Consequently, a principal components analysis (PCA) was applied to explore the interrelationships between the 22 items of the cause dimension of the IPQ-R, to form a subscale structure (Morris et al., 2002). All 22 causal items, including four items attributed to developing dementia (defined by dementia specialist clinicians), were subjected to a PCA using data from the person with dementia and the CG together. By applying a varimax rotation method, the chosen factors were rotated to interpret the pattern of the loadings for each component. Additionally, it was decided to combine the samples of both the person with dementia and the CG to produce a larger sample number in order to obtain a more robust factor solution.

On further examination of responses derived from the IPQ-R, discrepancies in responses given by the person with dementia and the CG were identified as being dissimilar to what would have been expected~~.~~ We reviewed unexpected responses at the item level and defined unexpected responses by using specific items that meant the same but were formulated in the opposite direction. For example, we compared the item content of “my dementia will last a short time” with that of “my dementia will pass quickly”.

Once all exploratory analyses had been conducted and variables within the data set finalised, Pearson’s correlation co-efficients of all scales with acceptable levels of Cronbach’s alpha were computed. This helped with the assessment of the inter-relationships between the predictor variables of the IPQ-R dimensions and the main outcome variable (GHSQ), as well as the HADS and EQ-5D, for both the person with dementia and the CG. To assess the reliability of the IPQ-R items of timeline, consequences, control, coherence, emotion, and cause, Cronbach alphas were conducted, and a cut-off score of items that were >.6 was deemed acceptable (Schmitt, 1996). The reliability of the IPQ-R identity scale was examined by applying the Kuder-Richardson 20 formula as an indicator of internal consistency, with scores >.7 considered acceptable. Kuder-Richardson can be seen as an equivalent to Cronbach’s Alpha but used for dichotomously scored items such as the identity scale (in this case, yes and no answers).

APIM Analysis

The APIM analysis was conducted using the web-based package for estimating the Actor-Partner Interdependence Model by Multi Level Modelling (APIM_MM, Kenny, 2015). This programme applies MLM, but no random effects are estimated; instead, the programme estimates the correlation of errors of the two members of the dyad. Thus, the analyses for the APIM by MLM applied generalised least squares with correlated errors and restricted likelihood estimation. The tests of correlations are based on correlation coefficients; the tests of coefficients are *Z* tests; and the degrees of freedom for error are taken to be infinite. Therefore, the *p* values for this programme are marginally smaller than those given by most MLM programmes; however, for studies with >50 dyads (as in this study) the difference is minimal. The effect size for actor and partner effects are partial correlations, and *d* is the dichotomous predictor (Kenny, 2015). The programme to compute the effect size are betas that are given twice, one using the overall (o) standard deviation among all participants, and a second using the standard deviation for the person with dementia and the CG separately (s). Thus, as betas are to be compared across all persons, the overall beta value was investigated. The alpha is set at .05 for all analyses. Chi -square analysis was applied to test for distinguishability (a meaningful factor between dyads), as observed distributions measured the relationship between the two variables, and thus dyad members were treated differently whether they were the person with dementia or the CG. Dyad-level covariates were also included in the model. We controlled for anxiety, depression, and quality of life as people with dementia and their CG experience higher levels of anxiety and depression compared to the general population of older adults (65+) (Shim et al., 2012). Table 8 below details the analytic framework applied for the APIM by MLM.

Table 8

Analytic Framework for APIM using MLM.

Objective	**Predictor/s**	**Dependent Variable**	**Analysis**
Model 1	Illness perceptions (PwD) (IPQ- R) (PwD). Illness perceptions (CG) (IPQ-R) (CG) Example of relevant covariates to be included in the model: HADS, EQ-5D.	Help-seeking intentions (PwD) GHSQ (PwD) after controlling for anxiety, depression, and quality of life.	Multilevel Linear Modelling - two - level model.

Model 2	Illness perceptions (CG) (IPQ-R –) (CG) Illness perceptions (PwD) (IPQ- R) (PwD.) Example of relevant covariates to be included in the model: HADS, EQ-5D.	Help-seeking intentions (CG) GHSQ (CG) after controlling for anxiety, depression, and quality of life.	Multilevel Linear Modelling - two - level model.

Note: PwD (person with dementia). CG (caregiver). IPQ-R (Illness Perception Questionnaire- Revised). GHSQ (General Help Seeking Questionnaire). HADS (Hospital and Anxiety & Depression Scale). EQ-5D (European Quality of life 5 dimensions).

Ethical Considerations

The study complied with NHS regulations and gained full ethical approval from the East of Scotland Research Ethics Service (EoSRES), in conjunction with NHS Health Research Authority (HRA) approval, plus ethical approval from Lancaster University Faculty of Health & Medicine Research Ethics Committee (FHMREC). Local approval from the SABP NHS Research & Development department was also gained. Participation in this study was voluntary and free from coercion, plus all participants had the opportunity to read a patient information sheet 48 hrs beforehand and were informed of any potential benefits and risks. Furthermore, all participants were given the opportunity to ask questions before signing the informed consent form. In the event of any problems with participation in the study, the patient information sheet provided people with dementia and their CGs the contact details of the Principal Investigator (PI).

It is considered that there was minimal risk to participants. However, people with dementia and their CGs are potentially vulnerable populations and great care was taken to avoid causing any distress during the conduct of the study.

Ethical Issues for People with Living with Dementia

Ethical issues may have arisen from individuals being upset with the diagnosis of dementia, and a lack of insight of having dementia once diagnosed; additionally, the CG may not have wanted to disclose this information to their relative/friend for fear of causing any upset. Considering this, the patient and carer information sheet contained relevant contact information (Local Patient Advice and Liaison Service (PALS)) should they have felt that they needed additional support/advice during the study. Furthermore, participants were advised that their normal care would not be affected in any way, and that taking part in the study would not impact on their usual treatment.

It was expected that there was no major risk for the researcher; however, it was acknowledged that the researcher was conducting questionnaires with people with dementia and their CGs and therefore might be exposed to the experiences of the illness and treatments during this time. The researcher was advised to seek out emotional support via regular clinical supervision, or from the Surrey & Borders Partnership Foundation NHS Trust (SABP) staff counselling services. As the researcher was administering questionnaires in the participants' homes, the SABP lone policy was adhered to. As part of this, the researcher used the "buddy" system, leaving details of the participants' address with a trusted colleague and would text the nominated colleague before they entered the participant's home, and again when they left. If the researcher noticed any safeguarding issues when visiting participants, the researcher discussed with participants any concerns and informed them that they may be contacting their care team.

Data Protection

In accordance with the Data Protection Act (1998), all participants were given a study ID number and any personalised data (e.g., consent forms, NHS number and date of birth) were kept separate from questionnaires to protect confidentiality. Data was stored securely in a locked filing cabinet with only the researcher having access to the cabinet key. Also, all of the data was transferred to electronic access-controlled databases and was encrypted, and password protected and only accessible by the researcher. All databases were backed up by the SABP NHS IT system, plus data was stored in Lancaster University’s secure encrypted storage system and archived for 10 years. Following completion of data analysis and submission and dissemination of the thesis, all personal details will be destroyed. All study data will be archived and stored securely for a minimum of 10 years at the SABP Trust HQ archive department.

Chapter 5: Findings

This chapter aims to present an overview of the findings of the study, providing an account of analytic techniques applied. The chapter will also outline the key findings in response to the research hypothesis and objectives.

Sample Characteristics

Due to COVID 19 restrictions a total 56 people with dementia (59% males) and their caregivers (CGs) (70% females) took part in the study, totalling 112 participants. People with dementia were significantly older (M = 78.95 SD = 7.47) than CGs (M = 71.54 SD = 11.30, t (93.37) = 4.09, p = .001). The gender category revealed a significant difference between person with dementia and CG, X^2 (1, n = 112) = 9.25 p = .002, with more females being CGs than males. Most of the total sample (N = 112) were white British (98%) and retired (87%) with the majority of CGs being spouses (79%). Regarding education, out of the total sample of both the person with dementia and the CG, most had either vocational qualifications (47%) or a bachelor's degree (53%). For education there was no significant difference between person with dementia and the CG, X^2 (1, n = 111) = .26, p = .78. For the employment category there was a significant difference between the person with dementia and CG, X^2 (1, n = 111) = 8.35 p = .004, with 95% of people living with dementia, retired, compared to 77% of CG's. With reference to the medical records, diagnosed by a consultant psychiatrist (ICD-10), Alzheimer's disease was the most reported type of dementia (86%), with 10% vascular dementia, 2% Lewy body and 2% mixed. Missing data from the survey was negligible. Table 9 outlines the demographics of the sample for the person with dementia and the CG with means and *SDs*.

Table 9

Characteristics of the Person with Dementia and Caregiver (n=56 dyads)

Variable	Person with Dementia *Mean (SD)* or percentage (%)	Caregiver *Mean (SD)* or percentage (%)
Age	78.95 (7.47)	71.54 (11.30)
Gender		
Males	33 (58.9 %)	17(30.4%)
Females	23 (41.1%)	39 (69.6%)
Ethnic Group		
White	56 (100%)	54 (96.4%)
None-White		1 (1.8%)
Irish		1 (1.8%)
Employment		
Paid employee	1 (1.8%)	9 (16.1%)
Retired	54 (96.4 %)	43 (76.8%)
Disabled	1 (1.8%)	2 (3.6%)
Self employed		1 (1.8%)
Education		
No qualifications	3 (5.4%)	-
O level/GCSE	14 (25%)	11 (19.6%)
A level	5 (8.9%)	4 (7.1%%)
Vocational Qualifications	11 (19.6 %)	20 (35.7%)
Bachelor's degree	16 (28.6%)	15 (26.8%)
Master's degree	3 (5.4%)	3 (5.4%)
Professional degree		2 (3.6%)
Doctoral degree		1 (1.8%)
Relationship between dyads		
Spouse/Partner	44 (78.6%)	
Daughter/Parent	7 (12.5%)	
Son/Parent	3 (5.4%)	
Friend	2 (3.6 %)	

Descriptive Statistics of Illness Perceptions for the IPQ-R Identity and Cause Subscale

Scores for the IPQ-R identity scale ranged from 1 – 30 with a mean of 9.32 (*SD* = 6.89) for the person with dementia, and the range of scores for CG were 2-32 with a mean of 15.05 (*SD* = 7.08). Based on the sum score of ‘yes’ responses from the identity scale, most of the people with dementia reported that they had experienced memory loss since receiving a diagnosis (77%), with 75% of them reporting that the symptom of memory loss was related to their dementia. There was a similar response from the CGs, with 96% reporting that the person with dementia had experienced memory loss since their diagnosis and that this was related to having dementia. With regards to the symptom of anxiety, 52% of the people with dementia stated that they had experienced anxiety since being diagnosed, with 38% of them relating anxiety to having a diagnosis of dementia. Also, the anxiety symptom was reported highly by the CG with 80% of CGs stating that the person with dementia had experienced anxiety since being diagnosed and 71% of CGs reporting that this was related to their dementia. Fatigue was the third most reported symptom with 68% of CGs expressing that the person with dementia had experienced fatigue since receiving a diagnosis, and 63% of CG’s naming that this was related to having dementia.

The most individual endorsed item relating to the causal dimension of the IPQ-R was ageing with both persons with dementia and their CGs attributing ageing as the main cause for dementia (66%), with 48% of persons with dementia and 38% of CGs reporting chance/bad luck as a cause. For CGs, 40% reported that stress and worry was attributed to developing dementia, as did 32% of the people with dementia.

Factor Analysis of the IPQ-R Cause Subscale.

We conducted an exploratory factor analysis of the items of the cause subscale to identify groups of causal beliefs as recommended by Hagger and Orbell (2005).

We applied a principal component analysis (PCA) to explore the interrelationships between the 22 items of the cause scale to form a new subscale structure (Morris et al., 2002), using the person with dementia and CG data together. Prior to performing PCA using a varimax (orthogonal) rotation, the suitability of the data was assessed. The Kaiser-Meyer-Olkin value was .734, exceeding the recommended value of .6 (Kaiser, 1970, 1974) and Bartlett's Test of Sphericity (Bartlett, 1954) reached statistical significance supporting the factorability of the correlation matrix.

Eigenvalues and a visual inspection of a scree plot were examined (Catell, 1966) in order to determine the number of factors to be retained. After inspection of factor solutions using both methods, a three-factor solution was considered to be the best option. All individual items comprising the cause subscale exceeded the minimum loading to be considered robust (i.e., .32 Tabachnick & Fidell, 2001), with the lowest loading being 0.323. All items loaded positively except for items of heredity and aging which did not load onto any of the three factors, thus items with the higher loadings were retained and hereditary and aging items were omitted from final analysis to form new Individual subscales.

The three-factor solution explained a total variance of 48.2%. with factor 1 comprising of eight items and contributing to 27.71% of the variance. Factor 2 was comprised of six items and contributed to 13% of the variance. The third factor comprised of four items and contributed to 7.5% of the variance (see table 2 for item content for all three factors). After an evaluation of the item content, the factors were named as "risk factors" (8 items), "behaviour & physical health factors" (6 items), and "psychological stress" (4 items). The rotated component structure (Varimax rotation) and loadings (> .3) for each item are outlined in Table 10 below. Items with factor cross-loadings are also presented in the table.

Table 10

Rotated Factor Matrix from Principal Components Analysis of IPQ-R Causal Items.

Causal Items	**Risk Factors**	**Behaviour & Physical factors**	**Psychological stress**
Stress/worry			.617
Hereditary			
Germ/virus	.712		
Diet/eating habits	.476		
Chance/bad luck	.581		
Poor medical in past	.723		
Pollution	.729		
Own behaviour	.686		**0.323**
Mental attitude			.759
Family problems	**0.450**		.610
Over-work	.470		**0.349**
Emotional state			.786
Ageing			
Alcohol		.827	
Smoking		.807	
Accident/Injury	**0.382**	.473	
My personality		.519	
Altered Immunity	.452	**0.423**	
Obesity		.721	
Diabetes		.708	

Note:(Bold figures indicates items loaded onto two factors aiding decision of where these items sit)

Descriptive Statistics and Reliability Scores for the IPQ-R, GHSQ, HADS and the EQ-5D

Cronbach's Alpha coefficients were calculated for each illness perception dimension of the IPQ- R subscales, plus the GHSQ, HADS and EQ-5D scales as to assess for internal consistency (Table 3). Acceptable levels of Cronbach's Alpha ideally should be above .7 (De Vellis, 2003), however alpha levels can be quite sensitive to the number of items in the scale (< 10). Thus, a further exploratory analysis was conducted examining item response patterns within each of the IPQ-R subscales that exhibited a low Cronbach's Alpha scores (<.6). These subscales were timeline acute/chronic, personal and treatment control, consequences, and coherence. We reviewed the response pattern at the item level and defined unexpected responses by using specific items that meant the same but were formulated in the opposite direction. For example, we compared the items "my dementia will last a short time" with "my dementia will pass quickly". (see below for detailed analysis, and table 12).

For the IPQ-R identity subscale the Kuder-Richardson 20 formula (KR-20) = .895 for the person with dementia and .873 for the CG, indicating good item total correlations. The GHSQ for the person with dementia demonstrated acceptable internal consistency (.799) also for the CG as well (.767). The HADS for both the person with dementia and CG also proved acceptable with scores of .818 and .816, respectively.

The EQ-5D for CG demonstrated acceptable internal consistency (.740) however for the person with dementia the score was comparatively low (.483). The reliability scores for all the IPQ-R items are displayed in Table 11.

Table 11

Descriptive Analysis and Internal Consistency Data for IPQ-R subscales, GHSQ, HADS & EQ-5D

Variable (scale)	**No of items (Maximum score)**	**Person with Dementia *Mean (SD)***	**Cronbach's Alpha**	**CG *Mean (SD)***	**Cronbach's Alpha**
Identity (IPQ-R)	20 items (max score = 40)	9.32 (6.82)	.895	15.05 (7.08)	.893
Timeline/acute/chronic (IPQ-R)	6 items (max score = 24)	16.4 (3.77)	.592	20.33 (3.56)	.544
Timeline cycle (IPQR)	4 items (max score = 16)	6.30 (3.19)	.842	8.4 (3.54)	.864
Consequences (IPQ-R)	6 items (max score = 24)	12.08 (4.11)	.603	16.1 (3.46)	.535
Personal control (IPQ-R	6 items (max score = 24)	12.67 (3.0)	.416	10.32 (4.10)	.636
Treatment control (IPQ-R)	5 items (max score = 20)	9.50 (2.54)	.299	8.53 (3.25)	.540
Illness coherence (IPQ-R)	5 items (max score = 20)	11.12 (4.27)	.321	12.41 (3.91)	.288
Emotion (IPQ-R)	6 items (max score = 24)	10.71 (4.56)	.637	14.25 (4.30)	.759
Risk Factors (IPQ-R)	8 items (max score = 32)	9.32 (5.05)	.752	8.69 (5.4)	.827
Behaviour & Physical Health (IPQ-R)	6 items (max score = 24)	4.47 (4.64)	.823	4.83 (4.47)	.756

Psychological stress (IPQ-R)	4 items (max score = 16)	4.78 (3.57)	.713	5.62 (3.44)	.804
Help seeking (GHSQ)	20 items (max score = 140)	53.71 (18.11)	.799	65.19 (16.89)	.767
Anxiety (HADS)	7 items (max score = 21)	3.92 (3.82)	.818	7.08 (3.94)	.816
Depression (HADS)	7 items (max score =21)	4.64 (3.75)	.735	5.08 (3.27)	.756
Quality of life (EQ-5D)	5 items (max score =10)	1.35 (1.35)	.483	1.53 (1.68)	.740

Note: IPQ-R = CG= Caregiver, Illness perception questionnaire revised, GHSQ = General Help Seeking Questionnaire, HADS = Hospital and Anxiety Questionnaire, EQ- 5D = European quality of life- five dimensions.

Analysis of Item Response Patterns of the IPQ-R scales with Low Reliability Scores (alpha < .6)

This analysis revealed that some of the responses were dissimilar to what would have been expected, relating to the description of the content being understood correctly. A number of responses revealed unexpected answers. An example as outlined below in table 12 is in relation to question IPQ-R 4 which relates to the persons perception of the chronicity of dementia. Results showed, out of a possible score of all 56 participants, 18 people with dementia and 34 CGs' response to questions IPQ-R 4 revealed contradictory answers, suggesting a lack of understanding of what the specific question was asking. Examples of analysis for each subscale are outlined in Table 12 and displays relevant comparative IPQ-R items, with discrepancy scores indicating the number of unexpected items. The pattern of responses suggests that this may be a contributary factor to the low reliability scores for specific subscales. After considering these observations we decided to utilise only the IPQ-R subscales with Cronbach's Alpha of >.6 for subsequent Pearson's correlations analyses.

Table 12

Example of Responses from IPQ-R Subscales (timeline, control, consequences, coherence)

Item number/subscale	Item content	Item number	Compared item content	Discrepancy in answers for the PWD (%)	Discrepancy in answers for the CG (%)
IPQ-R1 (timeline)	My dementia will last a short time	IPQ-R3	My dementia will last a long time	7/56 (12.5%)	6/56 (10.7%)
IPQ-R 4 (timeline)	My dementia will pass quickly	IPQ -R2	My dementia is likely to be permanent rather than temporary	18/56 (32.1%)	34/56 (60.7%)
IPQ -R15 (personal control)	Nothing I will do will affect my dementia	IPQ-R12	There is a lot I can do to control my dementia	13/56 (23.2%)	10/56 (17.8%)
IPQ-R19 (treatment control)	There is very little that can be done to improve my dementia	IPQ-R20	Treatment will be effective in curing my dementia	15/56 (26.7%)	4/56 (7.1%)
IPQ-R 6 (consequences)	My dementia is a serious condition	IPQ-R8	My dementia does not have much effect on my life	16/56 (28.5%)	28/56 (50%)
IPQ -R 24 (coherence)	My symptoms of dementia are puzzling to me	IPQ-R28	I have a clear picture of understanding my dementia	13/56 (23.2%)	8/56 (14.2%)

Note: PWD=Person with Dementia, CG= Caregiver, IPQ-R = Illness perception questionnaire revised

Correlations between the IPQ-R, GHSQ and the HADS and the EQ-5D

Pearson's correlation coefficients of all scales with Cronbach's alpha of >.6 were computed to assess the inter-relationships between the predictor variables of the IPQ-R dimensions with the main outcome variable (GHSQ) for both the person with dementia and the CG.

There was a significant positive correlation between identity and help seeking for the person with dementia (*r* = .26, *p* = .046), suggesting that more symptoms that are attributed to dementia by the person with dementia will endorse a greater inclination to seek help, and denotes a small effect. For the CG there was only one significant positive correlation between behaviour and physical health factors (one of the causal subscales) and help-seeking (*r*= .34, *p* = .009) denoting a medium effect size, suggesting stronger held causal beliefs of the role of individuals' own behaviour and physical health in causing dementia were associated with a greater inclination to seek help.

Correlations were also examined between the IPQ-R sub scales with anxiety and depression (HADS) and quality of life (EQ-5D). Results revealed that for the person with dementia there was a significant positive correlation between identity and anxiety (*r* = .32, *p* = .016) and depression (*r* = .36, *p* = .005. Also, there was a significant positive correlation for the person with dementia between the EQ-5D and Identity (*r*= .52, *p*<.001) and also between causal beliefs of psychological stress and the EQ-5D (*r*=.32, *p*=.016). Results for the CG showed that for anxiety there was a significant positive correlation between identity (*r*= .28, *p* =.003) and for depression (*r*= .39, *p*=.005) suggesting that the more symptoms that the person with dementia and CG identified with dementia were associated with higher levels of anxiety and depression, and for the person with dementia the more symptoms of identity were associated with higher levels for the EQ-5D. As we can see from these correlations the effect sizes are small to medium. Table 13 below outlines correlations between these specific subscales.

Table 13

Correlations Between Predictor Subscales of the IPQ-R, GHSQ and Anxiety & Depression and Quality of Life (n=56 dyads)

Variable	GHSQ - PWD	Anxiety (HADS)- PWD	Depression (HADS) PWD	QUAL (EQ-5D) PWD	GHSQ - CG	Anxiety (HADS)- CG	Depression (HADS) -CG	QUAL (EQ-5D) CG
IPQ-R subscales								
Illness Identity	.26*	.32*	.36**	.52**	-.17	.28*	.39**	-.0.03
Timeline cyclical	-.22	-.02	.06	.008	.07	.20	.16	-.0.06
Emotional representations	.23	.31*	.26*	.24*	-.14	.27*	.18	0.04
Risk factors	.14	.04	.10	.03	.18	-.02	.08	-.01
Behaviour/Physical Health	-.11	-.17	- .04	-.21	.34**	-.06	-.02	-.11
Psychological stress	.12	.05	.16	.32*	.12	-.06	.05	.10

Note: PWD = Person with Dementia, CG= Caregiver, IPQ-R = Illness Perception Questionnaire Revised, GHSQ = General Help Seeking Questionnaire, HADS=Hospital & Anxiety & Depression Scale.

**p* < .05, ** *p* < .01.

APIM Analysis for the Effect of Distinguishable Dyads with the IPQ-R Identity Subscale and the GHSQ

The main purpose of this investigation was to examine the effect of illness perceptions on help-seeking intentions among people with early-stage dementia and their CGs, and the impact of the dyadic relationship on help seeking for themselves. To achieve this, we employed the Actor

Partnership Independence Model (APIM) using multi-level modelling (MLM) to examine the actor and partner effect of the IPQ-R on the person with dementia and the CG on the GHSQ.

With distinguishable dyads there needs to be some meaningful factor by which to distinguish the two individuals across the dyad. Therefore, for this present sample, we assumed that participants were distinguishable on the basis that the members are defined by the roles as either the person with dementia or CG and are distinguished because of the role that they play within the dyadic relationship (Kenny et al., 2006). Thus, our approach for using the model was to consider dyad members as distinguishable. The average measure of ICC = 0.68 with a 95% confidence interval from .588-.760, suggesting a moderate variation between - group differences.

We identified a significant positive correlation between the IPQ-R subscale of identity with the main outcome of help seeking as presented in table 14. Thus, firstly we tested the actor and partner effects of the IPQ-R identity subscale for the person with dementia and CG on their help-seeking intentions. The actor estimated effect for the CGs was not statistically significant *b* = - 0.72**,** *p*= .26) (Table 6, & figure 1). The two actor effects were statistically significantly different (*Z* = -2.21, *p* = .029). However, we observed a statistically significant actor effect for the person with dementia with the actor estimated effect (*b* = 1.42, *p*= .041). The standardised effect was (*r* = .274) which reflects a small effect size (see Table 14 for standardised values). This finding suggests that the effect of the person with dementia's own perceptions of strongly identifying with their dementia can influence their help-seeking intentions, suggesting a positive impact by increasing their tendency to seek help the more they identify with the illness.

As a reminder the actor effect is the effect of the individual's own illness perceptions on their help seeking behaviour, and the partner effect is the effect of the individual's own illness perceptions on the other member of the dyad help-seeking intentions for themselves. For example, the effect of the CG's own illness perceptions of identity on their own help-seeking is the actor effect, and the effect of the CG's own illness perceptions of identity on the person with dementia help-seeking intentions is the partner effect.

Regarding the partner effects, we did not observe a statistically significant effect from CGs to persons with dementia and for persons with dementia to CG. Therefore, it can be said that the person with dementia and the CG perceptions of identity of dementia does not have any influence on other members of the dyad help-seeking intentions. The combined actor and partner effect across both the person with dementia and CGs was not statistically significant (Table 15).

Table 14

Estimates of Separate Effect Sizes for the APIM for People with Dementia and CGs for Identity Items of the IPQ-R and the GHSQ (n=56 Dyads)

Variable	Role	Effect	Estimate	95.00% CI (LL, UL)	*p* value	Effect size *(r)*
GHSQ	PwDs		50.29	(38.88, <.001)	<.001	
	CGs		68.88	(57.96,79.80)	<.001	
IPQ-R Identity	PwDs	Actor	1.42	(0.07,2.76)	.041	.274
		Partner	-0.32	(-1.63,0.99)	.632	-.066
		K	-0.22	(-2.14,1.54)		
IPQ-R Identity	CGs	Actor	-0.72	(-1.97,0.53)	.261	-.153
		Partner	0.43	(-0.85, 1.71)	.514	.090
		K	-0.59	(-7.86, 6.89)		

Note: PwD= Person with Dementia, CGs= Caregivers, k= parameters of interdependence, APIM = Actor & Partner Independence Model, IPQ-R = Illness Perception Questionnaire Revised, GHSQ= General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level).

Table 15

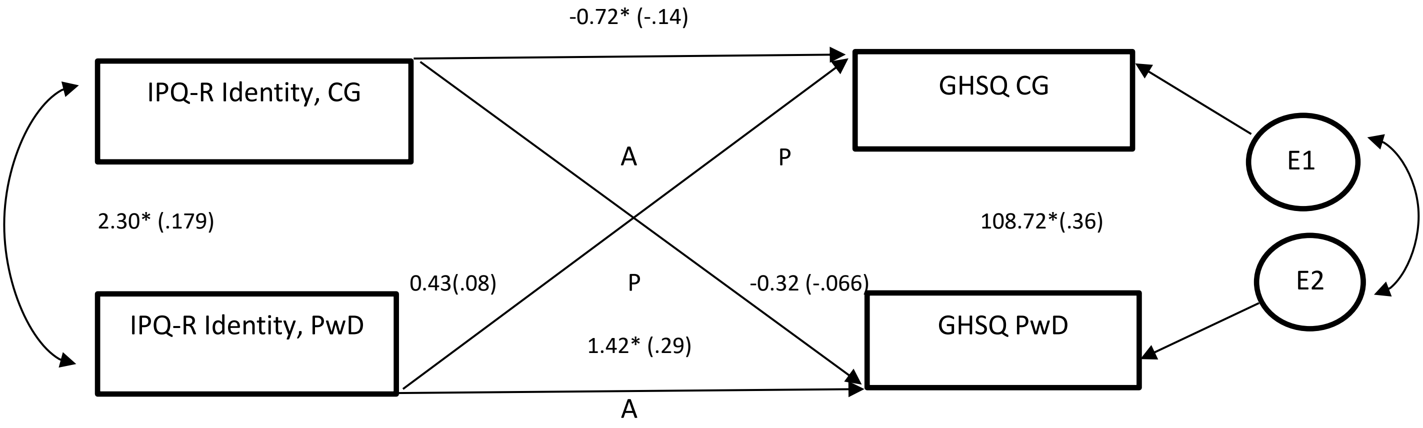
Estimates for the Overall Effect for the APIM for Identity Items of the IPQ-R and the GHSQ for People with Dementia and CGs (n = 56 Dyads)

Variable	Effect	Estimate	95.00% CI (LL, UL)	*p* value	Beta	Effect size (*r*)
GHSQ	Intercept	59.59	(50.37,68.80)	<.001		
Identity PwD	Actor	0.34	(-0.54,1.23)	.444	0.07	.072
	Partner	0.05	(-0.83,0.94)	.905	0.01	.011
	k	0.15	(-8.88,9.12)			

Note: PwD= Person with Dementia, k= parameters of interdependence, APIM = Actor & Partner Independence Model, IPQ-R = Illness Perception Questionnaire Revised, GHSQ= General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level).

Figure 4

Standardised Actor & Partner effects of the IPQ-R Identity Item Scores with GHSQ Score for the Person with Dementia and CG (n=56 Dyads)



Note: PwD = Person with Dementia, CG = Caregiver, GHSQ= General Help Seeking Questionnaire. A =Actor effect, P= Partner effect, * p <.05. Figures in parentheses denote standardised effects.

When we added the covariates of anxiety and depression with the identity items, there was < 0.5 of the explained variances for the dataset of people with dementia and their CGs. This suggests that these variables do not contribute significantly to explaining the patterns observed within the data and therefore were removed from the subsequent analysis (Kenny, 2015). Therefore, we repeated the APIM_MM analysis for the IPQ-R identity items, controlling for only the quality-of-life covariate.

After controlling for quality of life with the IPQ-R identity items, we did not observe any actor effects for person with dementia (*b* = 0.23, *p*=.10) or the CG (*b*= 0.76 *p*=.23). The two actor effects were not statistically significant (*Z*=-1.95, *p*=-.07).

APIM Analysis for the Effect of Distinguishable Dyads with the IPQ-R Subscale of Cause with the GHSQ

We then examined the actor and partner effect of the person with dementia and the CGs' IPQ-R physical/ behaviour causal scores with the GHSQ.   We observed a statistically significant actor effect for the CG, with the actor estimated effect (*b* = 1.20, *p*=.016) and with a standardised effect of (*r* =.32) which denotes a medium effect size. We did not observe any actor effects for the physical/behaviour causal beliefs for the person with dementia (Table 16). The test for the two actor effects were statistically significant (*Z*= 2.15, *p*= .033). These findings suggest that a CG's own perception of the physical and behavioural causes of dementia can positively impact on their help-seeking intentions.

We did not observe any partner effects from CGs to people with dementia or from people with dementia to CGs. The test for the two partner effects were not statistically significant different from each other (*Z*= -0.76, *p*= .44). Therefore, it can be concluded that the person with dementia and the CG perceptions of the physical and behavioural causes of dementia did not have any influence on other members of the dyad's help-seeking intentions. The combined actor and partner effects across both the person with dementia and CGs were not statistically significant (Table 17).

Table 16

Estimates of Separate Effect Sizes for the APIM for People with Dementia and CGs for Physical/ Behaviour Items of IPQ-R and the GHSQ (n=56 Dyads)

Variable	**Role**	**Effect**	**Estimate**	**95.00% CI (LL, UL)**	***p* value**	**Effect size *(r)***
GHSQ	PwDs		54.02	(45.12, <.001)	<.001	
	CGs		60.73	(52.87,68.59)	<.001	
IPQ-R Physical & Behaviour cause PwD	PwDs	Actor	-0.32	(-1.37-0.72	.542	-.08
		Partner	0.24	(-0.84-1.33)	.660	.06
		k	-0.74	(-11.69-12.29)		
CGs		Actor	1.20	(0.24,2.16)	.016	.32
		Partner	-0.30	(-1.22- 0.62)	.525	-.08
		k	-0.25	(-2.02, -0.66)		

Note: PwD= Person with Dementia, CGs= Caregivers, k= parameters of interdependence, APIM = Actor & Partner Independence Model, IPQ-R, P&B cause = Illness Perception Questionnaire Revised, Physical & Behaviour cause, GHSQ= General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level).

Table 17

Estimates for the Overall Effect for the APIM for Physical/Behaviour Items of IPQ-R and the GHSQ for Person with Dementia and CG (n=56 dyads)

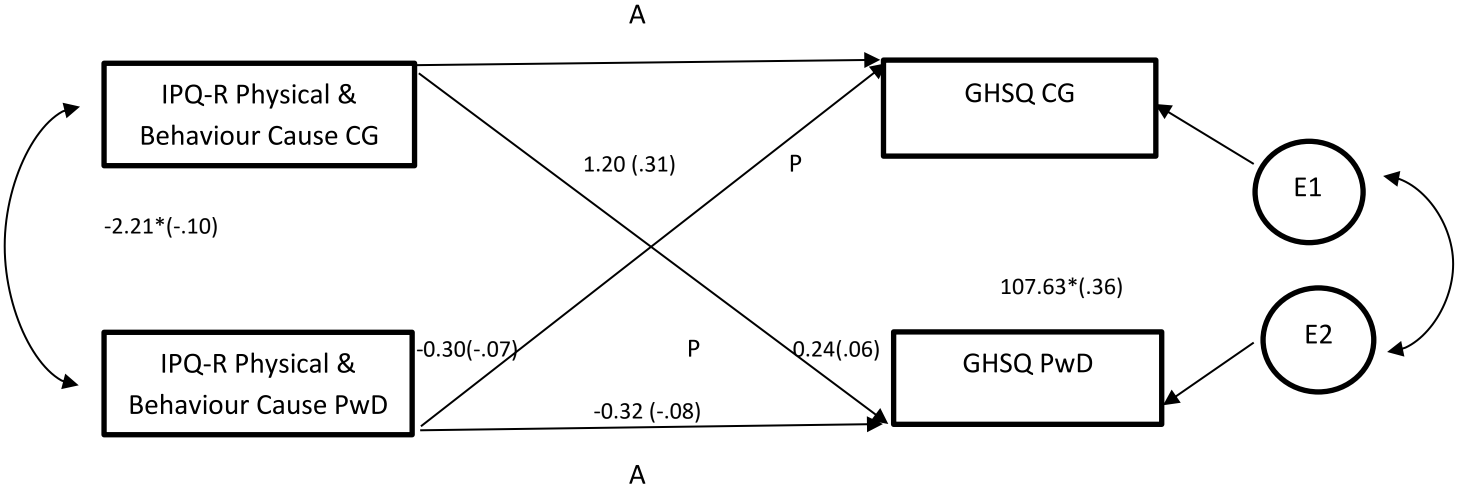
Variable	**Effect**	**Estimate**	**95.00% CI (LL, UL)**	***p* value**	**Beta**	**Effect size *(r)***
GHSQ	Intercept	57.38	(50.45,64.30)	<.001		
IPQ-R Physical & Behaviour cause PwD	Actor	0.43	(-0.28, .238)	.238	0.10	.116

Partner	-0.02	(-0.75, 070)	.940	- 0.007	-.007
k	-0.06	(-6.89, 6.50)			

Note: PwD= Person with Dementia, k= parameters of interdependence, APIM = Actor & Partner Independence Model, IPQ-R P&B cause = Illness Perception Questionnaire Revised Physical & Behaviour cause, GHSQ= General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level).

Figure 5

Standardised Actor & Partner Effects of the IPQ-R Physical/Behaviour Item Scores and the GHSQ for the Person with Dementia and CG (n=56 Dyads)



Note: PwD= Person with Dementia, CG = Caregiver. GHSQ = General Help Seeking Questionnaire
A= Actor effect, P= Partner effect * p <.05. Figures in parentheses denote standardised effects.

Covariate of depression was removed from the analysis as it revealed < 0.5 of the total variances for the dataset for people with dementia and their CGs. This suggests that the covariate of depression had a very minimal impact on the influence of the overall variability of the data. After controlling for quality of life and anxiety with the IPQ-R and the physical & behavioural cause items, we only observed actor effects for the CG. The actor estimated effect for physical & behaviour cause and the GHSQ with covariate of quality of life for the CGs was (*b* = 1.21, *p*= .016) with a standardised effect of (*r* = .32) which is statistically significant and denotes a medium effect size. This suggests that the actor effect of the CG's own illness perceptions of physical and behaviour causes of dementia can have a positive effect on their inclination to seek help for themselves, after controlling for quality of life (figure 3). The test for the two actor effects were statistically significantly different, *Z* = 2.71 (*p* = .008).

The actor estimated effect for physical and behaviour cause and the GHSQ with covariate of anxiety for the CG was (*b*= 1.21 *p* = .016), with a standardised effect of (*r*-.32) was statistically significant and represents a medium effect size. This suggests that the actor effect of the CGs own illness perceptions of physical and behavioural causes of dementia can have a positive effect on their inclination to seek help after controlling for anxiety (figure 7). The test for the two actor effects were statistically significantly different, *Z*= 2.70 (*p* = .008). We did not observe any partner effects from the CG to the person with dementia, or from the person with dementia to the CG. Details of findings of the effect of covariates on IPQ-R physical and behaviour cause items with the GHSQ and APIM analysis are outlined in tables 18 and 19 (quality of life) and tables 20 and 21 (anxiety).

Table 18

Estimates of Separate Effect Sizes for the APIM for People with Dementia and CGs for the IPQ-R Physical & Behaviour Cause Subscale with Covariate of QUAL and the GHSQ (n=56 Dyads)

Variable	**Role**	**Effect**	**Estimate**	**95% CI (LL, UL)**	***p* value**	**Effect size (*r*)**
GHSQ	PwDs		48.95	(39,80, <.001)	<.001	
	CGs		55.38	(46,12.64.64)	<.001	
Physical & Behaviour PwD	PwDs	Actor	-0.64	(-1.59, 0.30)	.186	-.19
	PwDs	Partner	0.34	(-0.60, 1.29)	.142	.10
		K	-0.52	(-7.79, 6.16)		

Physical & Behaviour CGs	CGs	Actor	1.21	(0.24, 2.17)	.016	.32
		Partner	0.01	(-1.19, 0.68)	.591	-.09
		K	-.0.21	(-1.96, 0.72)		
QUAL PwD		1.41	1.73	(-0.28, 3.76)	.095	.15
QUAL CG		2.14	1.81	(-0.19, 3.83)	.080	.17

Note: PwD = Person with Dementia, CGs=caregivers, IPQ-R = Illness Perception Questionnaire Revised, QUAL= Quality of Life, GHSQ = General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level), k = parameters of independence.

Table 19

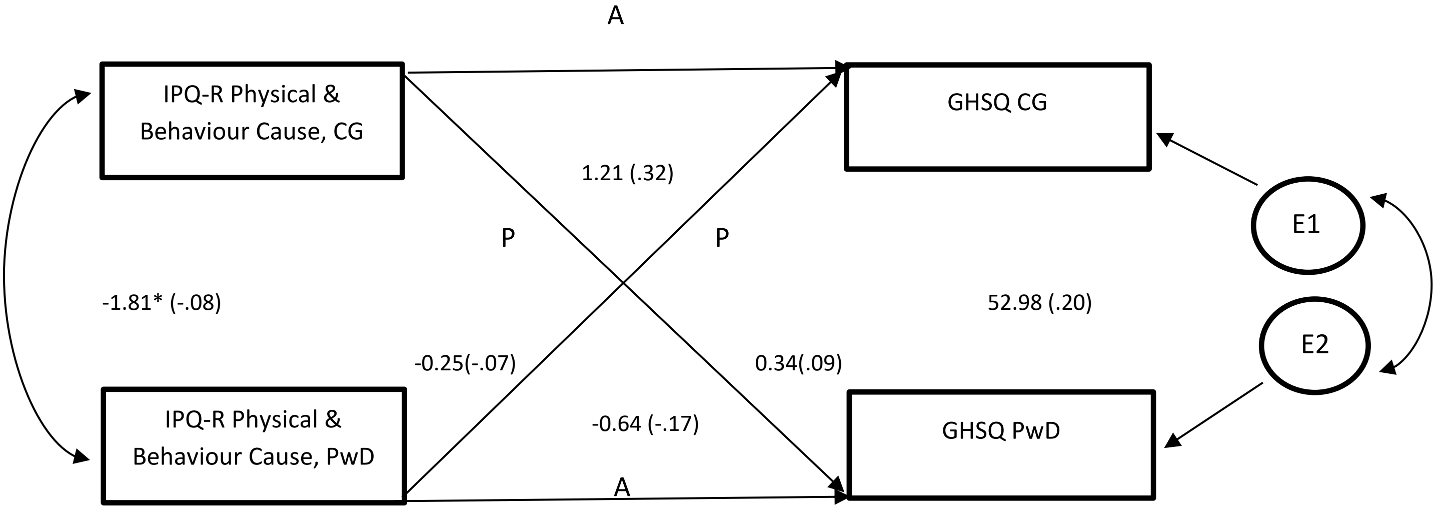
Estimates for the Overall Effect for the APIM for Physical and Behaviour Causal Items of the IPQ-R and Covariate of Quality of Life and the GHSQ for the Person with Dementia and CG (n=56 Dyads)

Variable	**Effect**	**Estimate**	**95.00% CI (LL, UL)**	***p* value**	**Beta**	**Effect size *(r)***
GHSQ	Intercept	52.16	(44.40, 59.93)	<.001		
IPQ-R Physical & Behaviour PwD	Actor	0.28	(-0.40, 0.96)	.419	0.07	.07
	Partner	0.04	(-0.63, 0.71)	.904	0.01	.01
	k	0.14	(-8.71, 9.06)			

Note: PwD= Person with Dementia, k= parameters of interdependence, APIM = Actor & Partner Independence Model, IPQ-R P&B cause = Illness Perception Questionnaire Revised Physical & Behaviour cause, GHSQ= General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level).

Figure 6

Standardized Estimates of Actor & Partner Effects of the IPQ-R Physical and Behaviour Item scores with Covariate of Quality of Life and the GHSQ for the Person with Dementia and CG (n-56 Dyads)



Note: PwD= Person with Dementia, CG = Caregiver. IPQ-R = Illness Perception Questionnaire-Revised, GHSQ = General Help Seeking Questionnaire A= Actor effect, P= Partner effect * p <.05. Figures in parentheses denote standardised effects.

Table 20

Estimates of Separate Effect Sizes for the APIM for People with Dementia and CGs for the IPQ-R Physical & Behaviour Cause items with Covariate of Anxiety and the GHSQ (n=56 Dyads)

Variable	**Role**	**Effect**	**Estimate**	**95% CI (LL, UL)**	**P value**	**Effect size (*r*)**
GHSQ	PwDs		52.02	(41.46, <.001)	<.001	
	CGs		57.74	(4.22.68.27)	<.001	
IPQ-R Physical & Behaviour cause PwD	PwDs	Actor	-0.66	(-1.63,0.31)	.189	-.214
	PwDs	Partner	0.32	(-0.66, 1.30)	.522	.101
		k	-0.48	(-7.24, 5.82)		
IPQ-R Physical &	CGs	Actor	1.21	(0.24, 2.19)	.016	.328

Behaviour cause CGs					
	Partner	-0.32	(-1.26, 0.62)	.506	-.105
	k	-.0.26	(-2.06, 0.67)		
Anxiety PwD		0.37	(0.42, 1.16)	.366	.113
Anxiety CG		0.10	(0.69, 0.90)	.801	.015

Note: PwD= Person with Dementia, CGs= Caregivers, k= parameters of interdependence, APIM = Actor & Partner Independence Model, IPQ-R = Illness Perception Questionnaire Revised, Physical & Behaviour cause, GHSQ= General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level)

Table 21

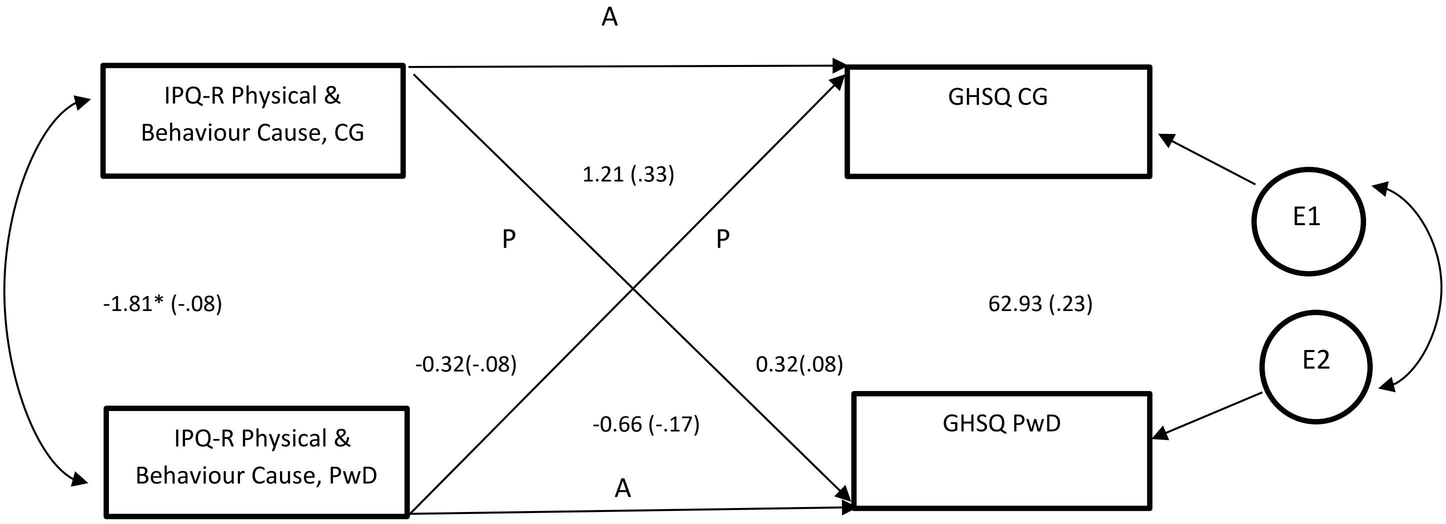
Estimates for the overall Effect for the APIM for Physical & Behaviour cause IPQ-R and Covariate of Anxiety and the GHSQ for the Person with Dementia and CG (n=56 Dyads)

Variable	**Effect**	**Estimate**	**95.00% CI (LL, UL)**	**p value**	**Beta**	**Effect size *(r)***
GHSQ	Intercept	54.88	(45.67, 64.12)	<.001		
IPQ-R Physical & Behaviour PwD	Actor	0.27	(-0.42, 0.98)	.438	0.07	.06
	Partner	0.00	(-0.69, 0.69)	1.00	0.00	.004
	k	0.00	(-9.93, 9.34)			

Note: PwD= Person with Dementia, k= parameters of interdependence, APIM = Actor & Partner Independence Model, IPQ-R P&B cause = Illness Perception Questionnaire Revised Physical & Behaviour cause, GHSQ= General Help Seeking Questionnaire, 95% CI, (LL, UL) = 95% confidence interval, (lower level, upper level).

Figure 7

Standardized Estimates of Actor & Partner Effects of the IPQ-R Physical and Behaviour Item scores with Covariate of Anxiety and the GHSQ for the Person with Dementia and CG (n=56 Dyads)



Note: PwD= Person with Dementia, CG = Caregiver. IPQ-R = Illness Perception Questionnaire-Revised, GHSQ = General Help Seeking Questionnaire A= Actor effect, P= Partner effect * p <.05. Figures in parentheses denote standardised effects.

The following chapter will consider these findings and seek to understand the complex and multi-faceted role of the IPQ-R in relation to the illness perceptions of people with dementia and their CGs and the relationship with help-seeking intentions, and the influence of the dyad relationship within this phenomenon.

Chapter 6: Discussion

Introduction

This chapter provides a discussion of the main study findings (as described in the previous chapter) with reference to the literature review and the methodology applied.

The concept of the SRM and the APIM will be discussed within the context of the findings for this present study. The limitations of the study are discussed with an emphasis on the challenges related to the use of the IPQ-R for people living with dementia, and suggestions for further developments for the IPQ-R. Finally, implications for future clinical practice, and research regarding theoretical advancement, are presented.

In summary, the main aim of this study was to examine the effect of the illness perceptions of the person with dementia and their CG on their help-seeking intentions for themselves, in respect of living with a diagnosis of dementia.

The main hypothesis was that the illness perceptions (beliefs about dementia) of the person with dementia and the CG would have an impact on their own help-seeking intentions after receiving a diagnosis of dementia. Therefore, higher scores on the IPQ-R subscales would indicate an increase in an individual's help-seeking intentions for themselves, after controlling for quality of life, anxiety, and depression.

Furthermore, it was predicted that partner effects of the person with dementia and the CG would be seen, and that these would relate to the illness perceptions of each dyad member (the person with dementia and the CG). This would then have an impact on their help-seeking intentions for themselves, both at an interpersonal and intrapersonal level, after controlling for quality of life, anxiety, and depression. To achieve this aim, we conducted a cross sectional survey with people with dementia and their CG.

Summary of Main Findings

To answer the main research question, four models were built and examined. To arrive at the final models, the reliability aspects of the scales and the pattern of correlations between the illness perceptions of the person with dementia and their CG with their own help-seeking intentions was taken into consideration. Four models were tested, one with illness perceptions of identity and one with illness perceptions of cause, as predictors of help-seeking. The analyses with these two models were also replicated with the addition of three potential confounders: anxiety, depression, and quality of life.

In the first model, without adjusting for confounders, a significant actor effect for the identity subscale for the person with dementia was found, where high scores on the IPQ-R identity subscale were associated with high scores on the GHSQ (r=.27, reflecting a small effect size). In the second model, with anxiety added as a confounder, the actor effect observed did not remain significant.

In the third model (without confounders) an additional statistically significant actor effect was observed for the physical/behaviour subscale for the CGs where high scores on the IPQ-R physical/behaviour subscale were associated with high scores on the GHSQ (r = .32, reflecting a moderate effect size). For the final model. with the added confounders of quality of life and anxiety, the findings remained significant for the CG for the physical/behaviour subscale with the added confounder of quality of life and anxiety.

In summary, hypotheses 1 and 2 were partially supported by these findings, when testing less restrictive models without confounders. However, hypothesis 3 was rejected in that no meaningful partner effects were observed. When adding confounders to the models, only one actor effect remained significant. However, extracting conclusions from these more stringent models could be considered challenging because of the small sample size.

A detailed discussion of the main findings follows below.

Actor Effects of Illness Perceptions of Identity Predicting Help-Seeking Intentions

Within the identity subscale for this study, general illness symptoms, plus eight specific symptoms related to dementia, were incorporated as one scale. High scores on this subscale were associated with a higher inclination to seek help (actor effect only, in a model without confounders). This finding is aligned with previous observations where an individual's own knowledge of dementia symptoms was associated with an increased intention to seek help from healthcare professionals (Giebel, 2017). Furthermore, in terms of theoretical consistency, Leventhal et al. (1998) demonstrated that the understanding of the symptoms of an illness can be related to beliefs of change and that the reaction to these beliefs of changes can influence help-seeking.

In support of the finding, previous studies into individuals with dementia have shown that symptom identity representations are all linked to help seeking (e.g.., Hall & Foushee 1993, Matthews et al., 1983); the findings from these two studies lend support to this study's findings with regard to help seeking strategies described by the SRM (Leventhal et al., 1980). Within the SRM, self-care behaviour such as help seeking can be viewed as problem solving when someone is faced with a health threat and can be influenced by an individual's own illness perceptions (Leventhal et al., 1980). Therefore, to make sense of this finding, I revisited Leventhal's position and suggested that the SRM framework was aligned with the predictions for this study's model. Therefore, the finding suggests that the SRM provides a useful framework to help understand the help-seeking intentions of the person with dementia in relation to their own symptoms of dementia. Thus, in relation to strongly identifying with the symptoms of dementia could be seen as having an influence on the person with dementia to seek help for themselves.

The lack of an actor effect for the CG for identity and help seeking suggests that identity was not a significant predictor for help-seeking for the CG. This may be related to the unpredictable nature of dementia. As dementia is a chronic condition and fluctuates over the course of the illness, the CG's decision to seek help may be affected by their own experiences of caring for someone with dementia. That is, the lack of an actor effect suggests that the CGs own perceptions of identity does not significantly influence their tendency to seek help (Harris & Titler 2021).

The combined actor and partner effect across both the person with dementia and the CG was not statistically significant. Furthermore, as this model focused on examining help-seeking intentions at one timepoint, the CGs' perceptions may not have been aware of the symptoms of dementia at a particular timepoint, whereas the person who was actually experiencing the symptoms of dementia may have been more motivated to seek help (Levkoff et al.,1999).

When anxiety was added as a confounder there were no significant actor or partner effects for identity and help seeking for the person with dementia. This suggests that the addition of anxiety within the identity model affected the outcome of help-seeking intentions for the person with dementia, suggesting that anxiety can have a negative impact on seeking help. This could be related to the person with dementia experiencing symptoms such as cognitive decline and reduced social interaction which may have affected the CG's feelings of anxiety, impacting, for instance their own feelings of anxiety. Thus, in this situation the person with dementia may be more dependent on the CG to seek help on their behalf, rather than seek help for themselves.

These findings regarding the most stringent model of actor effects are similar to findings from the literature review (chapter 2). Generally, the review revealed that difficulties in identifying symptoms of dementia was a barrier to help seeking, and we reported that identifying strongly with the symptoms of dementia for the person with dementia was related to help seeking.

However, it is important to note that the findings from the literature review revealed that strong cultural beliefs impacted on identification of the symptoms of dementia and that memory loss was often viewed as part of the aging process. In this present study, cultural attitudes in relation to identifying symptoms of dementia were not examined and furthermore most of the sample were

White British, which is a limitation in itself. Individuals from minority groups may be influenced by their own cultural beliefs about the symptoms of dementia and these beliefs may not match the model of treatment for dementia in more economically developed countries. Therefore, people from ethnic minorities who live in the UK may be reluctant to take up specific dementia care offered by dementia care professionals in the community (Mukadem et al., 2011). Examining the illness perceptions of these ethnic minority groups living with dementia could lead to the development of interventions with a more culture-specific approach (Giebel, 2017).

A discussion of the findings for the most reported symptoms for the identity subscale is presented in the following section.

Most of the people with dementia (77%) reported that memory loss was the main symptom related to dementia, with 96% of CGs reporting that memory loss was related to having dementia. These findings resemble other similar studies looking at illness perceptions of identity and dementia (e.g., Harman & Clare, 2006; Hamilton et al., 2010; Parveen et al., 2017; Altman and Werner, 2019) in which memory loss was identified as a main symptom related to dementia.

The second most reported symptom was anxiety, with 71% of CGs agreeing that this was related to dementia, and 38% of the people with dementia believing this. These figures support findings from a study examining illness representations and dementia caregiving by Sterzo and Orgeto (2017), in which caregivers were asked about their understanding of the disease. Their findings revealed that CGs associated psychological stress with the symptoms of dementia. This suggests that an increased awareness of dementia as a chronic disease may influence the CGs' psychological behaviour (e.g., by leading to high levels of burden, anxiety, and depression).

The findings imply that people with dementia and their CGs may benefit from early support and information in relation to the endorsement of the symptoms of memory loss and anxiety. Identifying what health beliefs in relation to the symptoms of dementia are most prominent for the individual would allow for easier management of subsequent treatment regimens, thus aiding more effective management of the illness, which has important implications in relation to their adjustments to living with dementia and seeking help (Clare et al., 2018).

Actor Effects for Illness Perceptions of Cause Predicting Help-Seeking Intentions

The cause subscale for this study reflects general causal attributions of an illness, as proposed by the IPQ-R, plus four additional dementia-specific causal attributions; these were diabetes, obesity, gender, and brain injury. The cause dimension was constructed of three subscales (risk factors, behaviour & physical health, and psychological stress). These subscales were identified through a factor analysis, representing the views of the person with dementia and their CG. Generally, high scores on a causal scale are linked to an individual's inclination to seek out help for themselves.

The significant actor effect finding for the CG indicated that a higher causal belief of behaviour/physical health was more highly associated with help seeking. Causal beliefs are important as they can influence attitudes around management of an illness. As the CG takes on more responsibility for caring for someone with dementia, this can influence their own help-seeking if they are more likely to attribute the physical and behavioural causes to dementia (Hamilton et al., 2010). The finding in this study supports this view in relation to the CG's perception of the cause of dementia, suggesting that causal attributes related to behaviour and physical health may be a predictor of seeking help.

In models with quality of life and anxiety as confounders, the cause subscale remained as a significant actor effect for behavioural and physical causal beliefs with help-seeking for the CG. Thus, the effect of the confounders of anxiety and quality of life may be related to the CG's awareness of their own perceptions of the causal beliefs for the person with dementia and may explain the variance in help seeking.

This finding suggests that despite the emotional strain associated with caring for someone with dementia, a CGs own beliefs about the causes of dementia can influence their own help seeking intentions (Lopes da Rosa et al., 2020) and seek help despite the extra responsibilities they are faced with regarding their perceptions of behavioural and physical causes related to dementia. This could be related to the CG making assessments about their previous experiences related to the physical and behavioural attributes of the person with dementia. This concept of using previous experiences to help an individual make sense of their illness is in line with a facet of the SRM, where an individual will develop illness perceptions of their condition by referring to symptomatic information based on current and previous experiences with the illness (Hagger & Orbell, 2003). Having an understanding of these causal beliefs and a relationship with previous lived experiences would help provide appropriate interventions, thus enabling people living with dementia to seek help and develop coping strategies after receiving a diagnosis of dementia (Quinn et al., 2018).

Presented below is a discussion of the factor analysis for the cause subscale, and the most reported causal beliefs of dementia.

Regarding consistency of the causal subscale, all three subscales were found to have high internal reliability scores, with logically expected associations with each other.

An Exploratory Factor Analysis (EFA) was conducted to establish the causal dimension subscale for people living with dementia and their CG. The EFA suggested that people with dementia and their CGs held causal beliefs pertaining to perceived risk factors, behavioural and physical factors, and psychological stress. These causal attributions are similar in nature to the three causal factors reported by Hagger and Orbell (2005) with cervical screening patients and Chilcott et al. (2012) for end stage renal disease. As this was the first attempt to measure the specific constructs within the causal subscale for people with a diagnosis of dementia and their CGs, these constructs can be argued to be acceptable, but to need viewing with caution; due to the relatively small sample size, the findings may not represent hidden causal factors pertinent to people living with dementia. This could pose a threat to future research findings, and it is suggested that further research could seek to replicate our current findings as to examine the current factor solutions for causal constructs. Out of the three subscales, only one subscale - that of behaviour/physical factors - showed a positive correlation with the GHSQ for the CG.

When asked to indicate their primary causal attributions, attributions made by the person with dementia and the CG perceived that ageing was the main cause of their dementia, with 66% of the people with dementia and the CGs indicating this too. Chance or bad luck was the second most perceived cause, with 48% of people with dementia and 38% of CGs reporting this. Stress and worry were also attributed as causes, with 32% of people with dementia and 40% of CGs reporting this. These findings are similar to those of other studies exploring illness perceptions and dementia. For example, Mukadem et al. (2011) cited stress and social isolation as a main causal attribute in the development of dementia; in addition, Clare et al. (2006) cited “normal” ageing as a common cause of dementia among people living with the condition.

However, interestingly, the ageing item of causal attributes for this study did not load onto any of the three factors, which suggests that the view of “normal” ageing among this cohort could have implications for the wording of this item. As the term “ageing” was used as a causal attribution, the item could not decipher the extent to which the person with dementia and the CGs were normalising the association between dementia and the ageing process, suggesting this item could either be a risk factor or a physical factor (Giebel, 2017). Moreover, several studies examining illness perceptions with other conditions have found the factor structure of the cause dimension hard to interpret and reported similar findings to this study (i.e., Moon et al., 2017). Furthermore, Giannousi et al. (2010), in a study of Greek cancer patients, found that ageing did not load onto any factor.

In this present study “ageing” was the most highly endorsed cause of dementia. Therefore, further investigations are needed to develop a more robust factor structure for the analysis of causal beliefs for older people with dementia and their CGs, particularly around the specific wording of items such as “ageing”.

Partner Effects for Illness Perceptions of Identity and Cause with Help-Seeking Intentions

The lack of partner effects for the person with dementia and the CG for cause and help seeking could be related to older people’s perceptions of the causes of dementia. As the mean age for both members of the dyad was > 70 years of age, they may have had similar individual perceptions of the causes of dementia. Older people may not be aware of risk factors such as diet/eating habits or hereditary factors playing a part in dementia developing (Giebel et al., 2017). Another reason for the lack of observing any partner effects may lie with the notion that dementia may not have a clear temporal event (cause and effect relationship) that precedes diagnosis, which in turn can make identification of causal attributes not easy to decipher. Therefore, people living with dementia may compare previous experiences of their own physical illnesses to try to make sense of their condition, as it is unlikely that they would have had any experience of neurodegenerative diseases in the past, and may not convey their own individual perceptions of the causes of dementia to each other (Matchwick et al., 2013)

The lack of partner effects in this study is similar to other dyadic research, where actor effects were found but effects between partners were missing (e.g., Ayotte et al., 2010; Gellert et al., 2018). For example, Gellert et al.’s (2018) study identified that dyadic coping was significantly associated with patients but not CGs. Our findings from this study may be related to the fact that even though the person with dementia recognises symptoms and changes within themselves, they may not communicate their concerns to the CG, and vice versa; this would have an impact on their help-seeking intentions. Reasons for this may relate to the attempts of the person with dementia to maintain their own autonomy in facing the changes they are experiencing. Therefore, the person with dementia would be working alone to keep things hidden and the CG could also be actively becoming more observant. Therefore, members of the dyad may be making an effort to cope and make sense of their circumstances but may be working separately rather than together (Chrisp, et al., 2012).

This notion is in line with the work of Keady and Nolan (2003), who reported that people in the early stages of dementia may well recognise changes in themselves but may conceal this from the CG. The authors go on to describe how working together is the best option, with early recognition of symptoms being shared and help being sought jointly. Keady and Nolan (2003) developed the concept of “working together” and “working separately” to describe the different kinds of relationship between a carer and the person for whom they care for. An example of working together is where a CG and the person with dementia discuss issues together and seek help from health professionals. On the other hand, an example of working separately is where a CG has not discussed matters with the person they care for and has sought help from health professionals independently.

Another explanation for the study outcome regarding the lack of partner effects may be related to the actual cognitive deficits caused by dementia and potentially the lack of insight by the person with dementia into their own cognitive abilities. This factor may affect the ability of the person with dementia to recognise the seriousness of the disease, which can be common even in the early stages of the disease (Miller et al., 2019).

A contributory factor to these findings may be related to the methodological features of the APIM, in relation to the impact of dyad members on their partner’s outcome. Orth et al. (2013) highlighted methodological bias with the use of self-report constructs when using the APIM as an analytical framework. Orth et al.’s (2013) study examined the actor and partner effects on personality with relationship satisfaction; their findings revealed that when using only self-report measures, actor effects were larger than partner effects. They proposed that when constructs are measured using one single method, such as self-report, the actor effect is based on information from one common source, whereas partner effects are based on information from different sources. Aligned with Orth et al.'s (2013) observation, one reason for not finding a significant partner effect could be related to the use of a self-report questionnaire. In the context of this study, solely self-report measures were relied on, and this may have affected the findings, as the person with dementia may have perceived their dementia as not that serious, whereas the CG's perception of dementia may have been more negative (Logsdon et al., 2002).

However, a study by Miller et al. (2019) which examined the dyadic effects of multiple dimensions of strain on the well-being of dementia care dyads reported more significant results than Orth et al. (2013). Findings showed a significant cross-partner effect for both the person with dementia and the CG's perceptions of relationship strain. Noticeably, they used only self-report measures as well, the Quality of life in Alzheimer's Disease questionnaire (QUAL AD, Logsdon et al.,1999), but did not apply the APIM, or any theoretical framework within the context of MLM. However, they integrated MLM with Latent Class Mixture Models (LCMM). LCMM allows the data to be preserved as dyads, while identifying specific patterns of perceptions, and this may account for their findings of cross partner effects (Miller et al., 2019). The nature of these dyadic studies demonstrates that the inter-related nature and quality of the dyadic relationship is a complex process, but important to an individual's well-being, and there is a growing consensus that there should be more dyadic research in the field of dementia (e.g., Braun et al., 2009).

Limitations

Regarding the limitations of this study, firstly the impact of COVID-19 on the recruitment of participants will be discussed, followed by an analysis of the data relating to the performance of the IPQ-R. Due to the importance of the usability of the IPQ-R for people living with dementia, this is discussed extensively and suggestions for further research made. Finally, limitations in respect of methodological decisions are discussed.

A strength of this current study is the low levels of missing data due to the researcher being present at the time of completion of the survey. However, the original sample size of 84 dyads could not be attained due to COVID-19 restrictions. Data collection involved the researcher completing the survey in participants' homes or hospital clinic settings. This method was deemed suitable for various reasons; firstly, to ensure that the person with dementia and the CG completed the survey separately, and to ensure that participants understood the instructions regarding completion of the survey. Secondly it was important for the researcher to be present to help and to explain the consent process, particularly if the person with dementia was experiencing cognitive difficulties. Therefore, in light of the methodological choices regarding the recruitment process, it was not possible to collect the required sample size of 84 dyads.

A smaller sample size of 56 dyads may have been a contributory factor in the number of non-significant correlations between illness perceptions and help-seeking intentions. Thus, the effect of certain illness perceptions (except for identity and cause) on help seeking outcomes may have been stronger, suggesting a type II error. A type II error suggests that there was no relationship between certain variables of the IPQ-R, when in fact there may have been if the sample size had been larger. Given the findings of this present study, it would be useful to replicate this model with a more diverse and larger sample to further examine the impact of the effect of the dyadic relationship on help seeking, thus contributing to further research in the care and well-being of people living with dementia.

Another limitation is that help-seeking from different categories of people such as family or friends or healthcare professionals may make a difference in how effective it is to predict behaviours. Thus, it may have been beneficial to examine different categories of help seeking with an individual's illness perceptions.

Examination of the Reliability of the IPQ-R for People Living with Dementia

In addition, as a result of access to the IPQ-R data, the reliability properties of this adapted version of the IPQ-R for people with dementia and their CGs was examined. The internal consistency for the use of specific IPQ-R subscales was deemed acceptable for dyad members (the person with dementia and the CG) for the subscales of identity, causal beliefs (risk factors, behaviour & physical factors, and psychological stress). The emotion subscale showed good reliability, but there were no significant correlations with the GHSQ. The GHSQ and the HADS questionnaires displayed acceptable internal consistency across both dyad members.

Despite support for two of the IPQ-R's subscales (identity and behaviour/physical cause), for the remaining subscales, there was a non-significant effect between illness perceptions and help-seeking intentions. These findings highlight differences in the way people responded to the IPQ-R and their perceptions of the disease in relation to timeline, control, consequences, coherence, and emotional representations. Reasons for this outcome may be due to various factors. One factor may be how the person with dementia and the CG understood and comprehended the questions in the IPQ-R, and this may have had an impact on our findings if there had been a decline in their cognitive function, and possible confusion of similar items being worded in an opposite format. This was particularly pertinent in the control subscales, which displayed very low reliability for both the person with dementia and the CG. This suggests that these types of questions may not be useful for people with dementia, due to fluctuations in cognitive difficulties associated with dementia (Arvanitakis et al., 2019). However, this response also related to the CGs, so this may suggest that the wording for control items is not suitable for CGs of people with dementia. As these items are aimed to capture CGs perceptions regarding their ability to manage the illness, it seems that specific aspects of this dimension need to be re-evaluated.

The development of the IPQ-R has enabled researchers to measure illness perceptions within a quantitative approach by assessing two main components of an individual's understanding of their illness, namely cognitive and emotional representations, and is explained within the SRM framework (Pedley et al., 2019). To the best of our knowledge, the application of the IPQ-R to measure illness perceptions among people with dementia and their CGs has not been done before. Thus, our findings suggest that the applicability of the measure is not best supported by the cross-sectional design. One reason for this finding could be the unpredictable and fluctuating nature of dementia, where some days can be better than others and may influence beliefs regarding the chronic timeline, personal and treatment control dimensions (Taylor et al., 2017). Hence, a longitudinal design may shed light on an individual's perceptions as they learn to live with dementia. For example, if the IPQ-R is administered to a person living with mild dementia when symptoms are less severe, they may rate the control and timeline of their dementia more positively than when symptoms become more severe. If an individual does not recognise the symptoms of dementia early on in the illness, this could delay individuals to seek help. Seeking help later on in the illness can reduce the effectiveness of health interventions for dementia care. Moreover, longitudinal studies have demonstrated the ability of the IPQ-R items to assess changes in illness perceptions over time, particularly in causal beliefs and personal control. As personal control and causal beliefs have been shown to change the most frequently in response to interventions, these beliefs are important for clinical implications and for future research into people living with dementia (Broadbent et al., 2015).

Aligned with the findings of this study, a systematic review of applying the IPQ-R with musculoskeletal patients found moderate test-retest reliability, and findings suggested that conditions that are prone to fluctuate, such as dementia, may affect the stability of a person's Illness perceptions (Leysen et al., 2015). Bains and Wittowski (2013) endorse this point in their review exploring illness perceptions in mental health, utilising the SRM. They suggest that there may be some conceptual challenges in the application of the SRM within the domain of mental health and propose that people's illness beliefs may not be stable over time, and thus that people might not maintain a consistent understanding of their illness. This could be the case with people living with dementia, as the more time elapses after their diagnosis, the less insight and awareness of the timeline of the disease they have. For example, the person with dementia may attribute ageing as a cause, while on the other hand describe themselves as having dementia, believing that the illness will improve over time.

The lack of internal consistency for the coherence subscale is consistent with Broadbent et al.'s (2015) review in which they report that illness coherence predicted the fewest outcomes. Their reasoning for this is that the Illness coherence dimension was added later by the original authors of the IPQ-R. This added dimension assessed how the patient's illness perceptions provided a coherent understanding of the illness. Consequently, less data exists in providing validity for the coherence dimension within the field of illness perception research. Moreover, Broadbent et al. (2015) propose that coherence can be seen as a summary of how other perceptions join together to provide a coherent model rather than being a separate perception. This lack of understanding of the meaning of the coherence dimension is reflected in the responses within the IPQ-R. For example, the IPQ-R 24 (reverse item) "my symptoms are puzzling to me "and the IPR-R 28 item "I have a clear picture of understanding my dementia" showed similar responses. This finding suggests that the individual may have found it difficult to comprehend the differences between the questions due to the negative wording of the reverse item.

Furthermore, when examining illness perceptions of the consequences of living with dementia, it is important to decipher what individuals believe to be important enough consequences of the illness to seek out help. For example, IPQ-R 8 “My dementia does not have much effect on my life” is quite a general statement as it does not clarify whether this relates to physical or psychological factors and the effect on the individual’s life. Therefore, the wording of the IPQ-R consequences domain in relation to the impact of physical and psychological factors, needs to take on a more targeted approach relating to the consequences of living with dementia.

Coherence of the disease is important for people living with dementia, as having knowledge of the illness is beneficial to targeting appropriate interventions (pharmaceutical or psychological) and the findings imply that people living with dementia could benefit from educational interventions which would help them have a better understanding of it (Quinn et al., 2018).

In regard to the good internal reliability scores for the identity, cause, cyclical timeline and emotional representation subscales, these findings are in line with previous research examining the reliability of the IPQ-R with cancer survivors (Moon et al., 2017), and with patients recovering from myocardial infarction (Brink et al., 2010). The timeline acute/chronic items of the IPQ-R produced conflicting responses in how long the person with dementia and CG saw dementia lasting, and demonstrated similar responses for personal and treatment control, consequences, and coherence. These responses may be linked to the low reliability scores and lack of internal validity of these items. Reasons for this are twofold; firstly, it may be the structure of the wording of the IPQ-R, as specific items are structured together within the same dimension but have a reversed component in them, which means participants may have found it difficult to understand what a specific question was asking. An example of this might be the wording of the timeline acute/chronic component of the IPQ-R 4 “my dementia will pass quickly” (reverse item) and the reverse, IPQ-R 2 “my dementia is likely to be permanent rather than temporary”.

Examples of the IPQ-R personal and treatment control subscale, where there were discrepancies in responses from the person with dementia and the CG, also suggested that the wording of the item may have been problematic for this cohort. For instance, the personal control item of IPQ-R15 (reverse item) “nothing I will do will affect my dementia” compared to IPQ-R12 “There is a lot I can do to control my dementia” produced conflicting comments. Also, there was a similar conflicting response within the treatment control questions: for example, IPQ-R19 (reverse item) “there is little that can be done to improve my dementia” compared to “treatment will be effective in curing my dementia”.

The timeline cycle describes the extent to which participants perceive their illness as fluctuating over time. As dementia is a chronic, slow progressing disease, it could be expected that people living with dementia will find any exacerbating symptoms difficult to comprehend. These may cause the person with dementia and the CG to lose confidence in their ability to control their illness, and thus be unable to distinguish between the acute and chronic dimensions of the IPQ-R (Fischer et al., 2010). Some authors have suggested modifications to items or the wording of items; for instance, Hagger and Orbell (2005) removed the timeline cycle sub-scale as this was deemed to not be relevant in the context of cervical screening. Secondly, it should be noted that time after diagnosis was not investigated in this current study, however as recently diagnosed people, those in the early stages of dementia, were being examined, a marked variability in outcomes was not expected.

Responses showed that participants responded to items similarly where different responses were expected. These findings support views of other researchers, who have noted problems with the control sub-scales. For example, Cabassa et al. (2008) reported possible respondent confusion in the understanding of the wording of the control items, notably those with negative wording, in measuring perceptions of depression. Confusing and ambiguous wording in respect of the term “control” and the resulting shortcomings are a problematic issue in psychometric measures; this is now causing a wider debate within the psychological literature arena around whether the control items are too generic or blunt and do not capture meaningful psychological variances (Snell et al., 2010). Also, the formulation of the treatment control items does not refer to a specific treatment, thus it is uncertain whether the participants were referring to dementia or general treatment. Furthermore, the amount of time elapsed since diagnosis is noted here, as the more time has elapsed after receiving a diagnosis can correlate with lower post-treatment perceptions of personal control (Fischer et al., 2010).

Moreover, the natural progression regarding difficulties of word comprehension and illness perceptions associated with old age may also be a factor, as the average age for CGs was 72 years and of people with dementia was 79 years. Chronological age can be an indicator that may moderate, or influence factors involved in the self-regulation process. Leventhal et al. (1998) suggest that older people (>65 years) are more sensitive to limitations in resources (social, biological, or psychological) and that older people are more prone to avoid risk. For example, a study by Leventhal et al. (1995) compared the mean time from first noticing a symptom to seeking care between middle aged (45-55yrs) and older respondents (65+). In summary, the older age group sought help from healthcare professionals more quickly, whereas the middle-aged group were willing to wait longer to seek help. However, Leventhal (1998) suggests that the differences are not just due to age, but also to strategies that are applied by the individual, as these differences in strategy may not occur between the same age group as in other geographical localities. Nevertheless, it is reasonable to assume that for this current study, the age of the person with dementia and their CG may have had an impact on their responses in relation to their illness perceptions of dementia. Older adults living with dementia have a lifetime of experiences and prior knowledge that may shape their illness perceptions, and these beliefs and expectations can have an impact on how they interpret the illness. Also, previous experiences with other illnesses or caring for others with similar conditions may impact their illness perceptions and coping strategies such as help-seeking.

Moreover, age – related changes in the regulation of emotions may explain the responses to the IPQ-R. Clare et al. (2022) posits that over time age changes the perspective of the future, leading to alterations in motivation, emotion regulation and adoption of coping strategies such as help seeking. Therefore, impacting on people who live with dementia to not seek help as they may want to avoid unpleasant outcomes, as to retain a positive outlook. From a carer's perspective, Quinn et al's (2017) study explored the illness representations of carers of people with dementia. The study highlighted the fact that carers tended to adopt diagnostic terms in describing the person with dementia illness, however, they were unsure about the control, cause, and timeline of the illness. This suggests that carers would benefit from a more tailored approach regarding management of caring for someone with dementia, and may explain the conflicting IPQ-R responses from the carers as they may have not been able to distinguish between the specific dimensions of the IPQ-R.

Lastly, although the APIM offers the researcher to measure the influence of dyad members have on each other, it is important to note that the measured variables (*X* and *Y*) may have had a different meaning to each member of the dyad. For example, the person with dementia may have construed a different meaning to the specific dimensions of the IPQ-R as compared to their carer. Therefore, this may have had an impact on the contradictory responses reported in the IPQ-R from both members of the dyad. This an important consideration regarding the equality of constructs when analysing quantitative data (Fitzpatrick 2016).

In respect of this study's findings regarding the useability of the IPQ-R, the findings could add to the development of a measure specifically focusing on dementia illness perceptions of people with dementia and their CGs (i.e., Quinn, Morris, & Clare, 2018).

Methodological Limitations

The use of a cross-sectional design for this study meant that illness perceptions of dementia and its relationship with help-seeking could not be explored over time. To gain further support for the applicability of the SRM for people living with dementia, research utilising the IPQ-R longitudinally by examining the long-term relationship between illness perceptions and help seeking could be considered (Broadbent et al., 2015).

Also, It is important to consider that the literature review specifically focused on help-seeking by applying a wide definition of people's illness perceptions of dementia. It would have been more beneficial to include a broader scope of illness perceptions of the literature as to capture a more comprehensive sense of illness perceptions among people living with dementia.

Moreover, it is possible that the lack of significant correlations between illness perceptions and help seeking may be due to limitations in the questionnaire used to measure help-seeking. The GHSQ was chosen for this study, as it covered a broad range of help-seeking strategies for use in the general population, as other help-seeking questionnaires focused more on specific groups (i.e., mental health patients, ethnic groups). Since the GHSQ is not specific to people living with dementia, the questionnaire may not have represented the views of people living with dementia and may have been limited in relevance to people seeking help for dementia, however questions did cover a broad range of help seeking for personal and emotional support. An example of a question from the GHSQ is as follows; "if you were having a personal or emotional problem, how likely is that you would seek help from the following people?"

Also, the ethnicity of the majority of participants was White British, all of whom were living in one geographical area. Examining illness perceptions of different ethnic minorities and in different geographical areas may yield further insights into people living with dementia and their help-seeking intentions. Additionally, qualitative research methods may prove beneficial in exploring additional themes of illness perceptions not currently presented within the IPQ-R measures and the SRM (Bains & Wittkowski, 2013). Conducting semi-structured interviews with the person with dementia and their CG to identify their perceptions of dementia and the connection between these and their help-seeking intentions could aid in the understanding of the dyadic effect (see, e.g., Stewart et al., 2021). Interviewing the person with dementia and the CG separately could allow for more insight into the impact of the dyadic relationship on the individual's own help-seeking intentions (Hill, 2005). Therefore, utilising a mixed method approach, both quantitative and qualitive approaches, may prove beneficial in detecting actor and partner effects within the APIM framework (Lester et al., 2022).

Implications for Practice and Recommendations for Future Research

The findings of this study have several implications.

Regarding clinical practice, illness perceptions of identity and cause were identified as significant predictors of help-seeking intentions. For the person with dementia, it was the belief that the more symptoms that they identified with the disease, the more they were inclined to seek help. For the CG it was the belief that they would be more inclined to seek help for themselves if they identified causal beliefs of dementia related to physical or behavioural factors. Thus, targeted interventions aimed at exploring the relationship between the symptoms and causes of dementia may lead to a better understanding of the illness and enhance an individual's self-care within the context of a shared management approach between both members of the dyad.

Given that a growing body of evidence shows that negative illness perceptions are associated with poorer health outcomes (Brink et al., 2011), it is important to further develop intervention designs. By building on the research findings from this study, future interventions may help improve knowledge and understanding of the illness perceptions of people living with dementia and the impact on their help-seeking behaviour. By combining research and clinical practice, the examination of the connection between illness perceptions and help seeking may provide an explanation in the assessment of cognitive and emotional representations for the management of people living with dementia within the community. As an individual's perception about the seriousness of their illness become less optimistic over time, future interventions should consider the individuals appraisal of their own health outcomes (Fischer et al., 2010).

Furthermore, better understanding of the illness perceptions of people with dementia as opposed to their CG in a dyadic context may inspire further developments for clinical interventions by enhancing a shared illness management approach between the person with dementia and their CG. Research has shown that people with dementia in the early stages of the disease can reliably report on their own preferences regarding their care (Miller et al., 2019). However, even in the early stages of the disease, CGs can take on a more prominent role in decision making regarding care plans and not necessarily communicate their plans with the person with dementia. In order for interventions to be effective, CGs need to be aware of the perceptions of the disease held by the person with dementia. Identifying the needs of the person with dementia, alongside the CG's perception of the disease, could bring about a more shared understanding of how best to live with dementia. One reason why people with dementia may not be able to communicate their perceptions of living with dementia could be down to the level of cognitive impairment. More tailored interventions that consider the cognitive difficulties of individuals with dementia may bring about a more shared understanding between both members of the dyad.

Exploring these specific facets further may improve the help-seeking outcomes of people with dementia and their CG as they adjust to living with the illness. This tailored approach is validated by self-regulation models, in that personalised interventions aimed at specific cognitive changes are likely to be more effective. Hence, interventions that consider the natural tendencies of the individual may result in differing responses to behaviour-change interventions (Abraham et al., 1998). Thus, a future examination of a self-regulatory approach in people living with dementia could consider what dementia symptoms create increased help-seeking intentions.

Further studies are needed to cross-validate the findings of this study. With further research, an adapted version of the IPQ-R focusing on specific dementia representations may enable researchers to examine the illness perceptions and help-seeking intentions of people with dementia, thus, aiding assessment of the impact of the dyad effect on illness perceptions and help seeking. Therefore, this present examination of illness perceptions and help seeking outcomes for people living with dementia could be seen as an initial step in the development of a more suitable version of the IPQ-R for this specific group of people.

Conclusion

The previous chapter discussed the findings outlined in chapter 5 and considered the use of the theoretical framework of the SRM (Leventhal et al., 1980, Leventhal et al., 1984) by examining the relationship between the illness perceptions of people living with dementia and their help-seeking intentions, alongside the influence of the dyadic effect supported by the APIM.

The SRM posits that the cognitive model that an individual constructs about their illness guides their coping behaviour, including help seeking. Although the model suggests that the cognitive model is influenced by external factors, the findings from this study in respect of the person with dementia and the CG being mutually independent of each other regarding help-seeking, suggests that a more shared approach to illness perceptions is not represented. Therefore, when examining dyadic influences, a broader socially constructed view of the illness perceptions of people living with dementia could be beneficial. For example, taking into account broader concepts such as the home environment, daily routines and unmet needs may help to provide a more in-depth understanding of the psychological determinants of the illness perceptions of people living with dementia and the relationship with help seeking.

However, this is the first study to examine illness perceptions and help-seeking in people with a diagnosis of dementia and their CGs by utilising the IPQ-R. A main strength of this study is that a thorough process informed the initial modification of the IPQ-R for use with dementia, with robust statistical analysis applied for reliability and validity. This modified IPQ-R model for dementia showed there were inconsistences regarding the reliability and validity of certain IPQ-R subscales, with high Cronbach's scores only for identity, cause, timeline cyclicality and emotion.

Furthermore, this is the first study to conduct a EFA on the causal belief's subscale for use with dementia and represented a cross section of people living with early-stage dementia and their CGs. The identity subscale items were also modified to include specific dementia items, thereby increasing the structural validity of this subscale. Furthermore, data were collected from both partners in the dyad, allowing for analysis of the factor structure of both actor and partner versions. This study has shown that the use of the APIM usefully served to examine the impact of the illness perceptions of people with dementia and their CGs on their help-seeking intentions. However, the small sample size limits the conclusions that can be drawn from this study and further research with a larger sample size may be beneficial.

This chapter also discussed the use of the IPQ-R questionnaire for people living with dementia and considered adaptions to the questionnaire regarding the use of language for specific item questions, notably the control dimensions. Future use of the IPQ-R for people living with dementia should be carried out longitudinally, rather than as a cross sectional design. The SRM is unique in that it proposes the influence of emotional representations on illness behaviours defining its outcomes in response to a specific health threat (Walsh et al., 2004). As people who live with dementia and those who care for them face daily challenges, previous experiences are important predictors of help-seeking behaviours.

Additionally, the observation of both actor and partner effects in this study suggests opportunities to improve the outcomes of the person with dementia, by developing interventions for both members of the dyad. The lack of partner effects suggests that future interventions could focus on a shared approach for people living with dementia by incorporating a shared understanding of their own illness perceptions. Evaluating these interventions at the early stages of the disease may help in identifying the processes involved in help-seeking. Thus, people could access support at point of need, rather than delaying seeking help to the time when symptoms become severe, and treatments might be less effective. Developing a more tailored approach that identifies an understanding of an individual's own health beliefs regarding the symptoms and the causes of dementia could help the person with dementia and their CG manage the illness more effectively together within the dyadic relationship (Shinan Altmen & Werner, 2019).

The value of this piece of research has been to open up the discussion on the issue of living with dementia in the early stages of the disease, and how people adjust and respond to their diagnosis. Examining the relationship between the illness perceptions and help seeking of the person with dementia and their CG as individuals, and also jointly as a couple, has placed both partners at the centre of the process of learning to live with the illness.

Chapter 7: Reflections and Conclusion

Reflections

This piece of research was conducted on a part-time basis. Balancing work commitments with PhD commitments proved to be a challenging process. Moreover, in part, this study took place during the COVID 19 pandemic. Experiencing lockdown and conducting meetings virtually could at times be an isolating process, and brought its own challenges, with loss of face-to-face connection with fellow students and peers. However, completion of this PhD brings about a great sense of achievement. I have developed many research skills and there has been an immense learning curve in respect of my academic writing skills and statistical analytical knowledge. I have further developed my knowledge of dementia and am grateful for other NHS research staff who have supported me.

The findings from this study provide a useful contribution to the theoretical advancement of the relationship between illness perceptions and help-seeking behaviour among people living with dementia. I hope this contribution encourages future researchers in this field. In particular, there remain important questions to address regarding research focusing on the perceptions of their illness held by the person with dementia, as this is a neglected area. Also, the effect of the dyadic relationship on both the person with dementia and the CG, both as individuals and dyads, needs to be incorporated into the examination of illness perceptions and help-seeking, as this is also under-researched.

Conclusion

Listed below are the key findings from this study, with suggestions for recommendations for future research.

Key Findings

- There was a significant actor effect for the person with dementia in respect of identity and help-seeking; however, after the addition of the covariates of quality of life and anxiety, there was no actor effect.
- There was a significant actor effect for the CG in respect of physical/ behaviour cause and help-seeking, and with the addition of the covariates of quality of life and anxiety, there was still a significant actor effect.
- There were no partner effects between the person with dementia and CG in respect of their own illness perceptions of dementia and their help-seeking intentions.

Recommendations.

- To consider adaptions to the IPQ-R for people living with dementia with regard to the language used for specific items, particularly those concerning the personal and treatment control questions.
- Regarding the IPQ-R, to consider an exploration of the symptoms that create a higher response for help-seeking in people with dementia.
- Utilise a mixed methods approach, considering the social perspective of people living with dementia, within the context of a longitudinal approach.
- In respect of the lack of partner effects, when considering adjustments to living with dementia, healthcare interventions should consider the wider social world of the person with dementia and the CG within the context of their relationship, so as to accommodate a model of shared illness management.

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Appendix 1

East of Scotland Research Ethics Service (EoSRES) **Research Ethics Service**

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

TAyside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Ms Jane Gregg PhD
Candidate
Surrey & Borders Partnership NHS Trust
Research & Development
Holloway Hill
Chertsey
KT16 0AE

Date: 10 July 2018
Your Ref:
Our Ref: LR/AG18/ES/0068
Enquiries to: Arlene Grubb
Direct Line: 01382 383848
Email: eosres.tayside@nhs.net

Dear Ms Gregg

Study title: Illness perceptions and help seeking intentions among people with early stage dementia and their caregivers REC reference: 18/ES/0068 Protocol number: 1 IRAS project ID: 243685

Thank you for your letter of 25 June 2018, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Alternative Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise). Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime, no study procedures should be initiated at non-NHS sites.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Sponsor Insurance letter]		30 June 2017
IRAS Application Form [IRAS_Form_09052018]		09 May 2018
IRAS Checklist XML [Checklist_09052018]		09 May 2018
IRAS Checklist XML [Checklist_09072018]		09 July 2018
Letter from sponsor [Sponsor Letter]		03 May 2018
Letters of invitation to participant [Expression of Interest]	V.2	25 June 2018
Sponsor Insurance letter		30 June 2017
Caregiver consent form	V.1.	23 April 2018
CV Jane Simpson	V.1.	
Caregiver information sheet	V.2	25 June 2018
Caregiver Survey	V.2	25 June 2018
Participant consent form [PWD Consent Form]	V.1.	23 April 2018
Participant information sheet (PIS) [PWD Information sheet]	V.2	25 June 2018
Research protocol or project proposal [Research Protocol]	V.1.	23 April 2018
Response to Request for Further Information		25 June 2018
Summary CV for Chief Investigator (CI) [CV Jane Gregg]		23 November 2017
Summary CV for supervisor (student research) [CV Perez Algorta]		08 April 2018
Validated questionnaire [PWD Survey & questionnaires]	V.1.	23 April 2018

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/qualityassurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/ES/0068	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Arlene Grubb

For Ms Petra Rauchhaus
Alternative Vice Chair

Email:eosres.tayside@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Becky Gordon

Ms Alicja Baniukiewicz, Surrey & Borders Partnership NHS Foundation Trust

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Ms Jane Gregg

PhD Candidate
Email: hra.approval@nhs.net
Surrey & Borders Partnership NHS Trust Research-permissions@wales.nhs.uk Research & Development

Holloway Hill

Chertsey

KT16 0AE

12 July 2018

Dear Ms Gregg

HRA and Health and Care

Study title:	**Illness perceptions and help-seeking intentions among people with early stage dementia and their caregivers**
IRAS project ID:	**243685**
REC reference:	**18/ES/0068**
Sponsor	**Lancaster University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales? You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your nonNHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including: ☐ Registration of research

- Notifying amendments

- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Jane Gregg
Tel: 07789399240
Email: j.gregg@lancaster.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **243685**. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede
Assessor

Email: hra.approval@nhs.net

Copy to: Ms Becky Gordon, Sponsor Contact

Ms Alicja Baniukiewicz, Surrey & Borders Partnership NHS Foundation Trust,
Lead NHS R&D Contact

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance letter]		30 June 2017
HRA Schedule of Events	2	11 July 2018
HRA Statement of Activities	1	15 June 2018
IRAS Application Form [IRAS_Form_09052018]		09 May 2018
IRAS Application Form XML file [IRAS_Form_09052018]		09 May 2018
IRAS Checklist XML [Checklist_09072018]		09 July 2018
Letter from sponsor [Sponsor Letter]		03 May 2018
Letters of invitation to participant [Expression of Interest]	V.2	25 June 2018
Other [Caregiver consent form]	V.1.	23 April 2018
Other [CV Jane Simpson]	V.1.	
Other [Caregiver information sheet]	V.2	25 June 2018
Other [Caregiver Survey]	V.2	25 June 2018
Other [Sponsor Insurance letter]		30 June 2017
Participant consent form [PWD Consent Form]	V.1.	23 April 2018
Participant information sheet (PIS) [PWD Information sheet]	V.2	25 June 2018
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Summary CV for supervisor (student research) [CV Perez Algorta]		08 April 2018
Validated questionnaire [PWD Survey & questionnaires]	V.1.	23 April 2018

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	A.65 left blank as funding has not been secured yet.

2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Sponsor intends to use the Statement of Activities as the form of agreement with the participating organisation.
4.2	Insurance/indemnity arrangements assessed	Yes	Valid insurance certificate submitted.
4.3	Financial arrangements assessed	Yes	Funding applications are in progress. Portfolio team have been notified by the applicant. In the event that funding is not secured, the applicant has confirmed they will still be able to conduct the study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any	Yes	No comments
Section	**Assessment Criteria**	**Compliant with Standards**	**Comments**
	applicable laws or regulations		
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	Provisional Opinion issued 13 June 2018. Further Information Favourable Opinion issued 10 July 2018.

6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a non-commercial student (PhD in Mental Health) study and there is one site type.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A PI is expected at the participating organisation.

GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

All study activities will be undertaken by local staff employed by the NHS organisation. Therefore no honorary research contracts or letters of access are expected for this study.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.
The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

Lancaster University

Applicant name: Jane Gregg

Supervisors: Guillermo Perez Algorta

Department: Health Research

3 May 2018

Dear Jane

Re: Illness perceptions and help-seeking intentions among people with early-stage dementia and their caregivers

The University of Lancaster undertakes to perform the role of sponsor in the matter of the work described in the accompanying grant application. As sponsor we assume responsibility for monitoring and enforcement of research governance. As principal investigator you will confirm that the institution's obligations are met by ensuring that, before the research commences and during the full term of the grant, all the necessary legal and regulatory requirements are met in order to conduct the research, and all the necessary licenses and approvals have been obtained. The Institution has in place formal procedures for managing the process for obtaining any necessary or appropriate ethical approval for this grant. Full ethical approval must be in place before the research commences and should be reviewed at all relevant times during the grant.

Yours sincerely,

Diane Harris

PP Professor Roger Pickup

Associate Dean for Research

Chair Faculty of Health and Medicine Research Ethics Committee.

Re: IRAS No: 243685 Confirmation of Capacity and Capability at Surrey & Borders Partnership Foundation NHS Trust.

AB

Alicja Baniukiewicz <Alicja.Baniukiewicz@sabp.nhs.uk>
To:

- Jane Gregg <Jane.Gregg@sabp.nhs.uk>

Mon 23/07/2018 09:19

Dear Jane,

RE: IRAS No: 243685 Confirmation of Capacity and Capability at Surrey & Borders Partnership Foundation NHS Trust.

Full Study Title: Illness perceptions and help-seeking intentions among people with early stage dementia and their caregivers

This email confirms that **Surrey & Borders Partnership Foundation NHS Trust** has the capacity and capability to deliver the above referenced study.

.
If you wish to discuss further, please do not hesitate to contact me.

Regards,

Alicja Baniukiewicz
Research Facilitator

T: **01932722704**
E: **Alicja.Baniukiewicz@sabp.nhs.uk**

Surrey and Borders Partnership NHS Foundation Trust
Research & Development
Abraham Cowley Unit
Holloway Hill
Chertsey
Surrey
KT16 0AE

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Reply
Forward

Appendix 2

Health & Medicine | Lancaster University

NHS
Surrey and Borders Partnership
NHS Foundation Trust
Older People's Mental Health Services

Participant Information Sheet (Person with Dementia)

Study Title*: Illness Perceptions and help seeking intentions among people with early stage dementia and their caregivers.*

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Jane Gregg, and I am conducting this research as a PhD student within the Division of Health Research (DHR,) Mental Health Programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is looking at the association between people's illness beliefs of dementia, and how this impacts on their intention to seek help. This information will be collected by a survey.

Why have I been approached?

You have been approached because the study requires information from people with dementia and the people that care for them (a caregiver could be a family member or a friend).

Do I have to take part?

No. It's completely up to you to decide whether you take part. Participation in the study is entirely separate from any health or social care you receive and will not affect your day to day care. If you decide not to take part, at any time, your decision will in no way compromise your rights and the standard of care you will receive.

What will I be asked to do if I take part?

The person that cares for you must also agree to participate with you. If you both choose to take part in the study a researcher will visit you both and ask you to complete some questionnaires about your health and wellbeing. Questionnaires may be completed electronically or by paper. It is expected that this will take no more than 45 minutes in total. If you require any help, the researcher will be able to assist you complete the questionnaires during this time.

Will my data be Identifiable?

The information you provide is confidential. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data. All data will be kept in accordance with the Data Protection Act.
It will not be possible to identify you in any articles or reports that are published from this study. Surrey & Borders Partnership NHS Foundation Trust will keep your name, and contact details confidential and will not pass this information to the sponsor, Lancaster University. Surrey & Borders Partnership NHS Foundation Trust will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study.

However certain individuals from Lancaster University may look at research records to check the accuracy of the research study. Lancaster University will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. Surrey & Borders Partnership NHS Foundation Trust will keep identifiable information about you from this study 12 months after the study has finished and will be destroyed thereafter.

Lancaster University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Lancaster University will keep information about you 10 years after the study has finished.

Your rights to access change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

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If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Our Data Protection Officer is Michael Abbots and details can be found by following link as before.

There are some limits to confidentiality: if anything reported makes me think that you, or someone else, is at significant risk of harm, I will need to break confidentiality and speak to a member of staff or your clinical care team. If possible, I will inform you if I need to do this.

What will happen to the results?

The results will be summarised and reported: in a dissertation/thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. Furthermore, the East of Scotland Research Ethics Service REC 2, which has responsibility for scrutinising all proposals for health and social care research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your research records from this study be made available for scrutiny by academic supervisors from Lancaster University, whose role is to check that this research is properly conducted and the interests of those taking part are adequately protected.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
Jane Gregg e-mail: j.gregg@lancaster.ac.uk

Project Supervisors: Dr Guillermo Perez Algorta: e-mail: g.perezlgorta@lancaster.ac.uk

Dr Jane Simpson. E-mail: j.simpson2@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Director of Studies:
Dr Sean Hughes Tel: (01524) 510847
Email: sean.hughes@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster
LA1 4YW

If you wish to speak to someone outside of the PhD DHR Mental Health Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Alzheimer's Society;
Tel: 0300 222 1122
Email: enquries@alzheimers.org.uk
Web: alzheimers.org.uk

Adult Social Care information and advice line (Surrey County Council)
Tel: 0300 200 1005
Email: contact.centre@surreycc.gov.uk
Web: www.surreycc.gov.uk/adultsocialcare

Advocacy Services:
Tel: 0800 3357330 (Freephone).
Email: info@advocacyinsurrey.org.uk

Patient Advice & Liaison (PALS) and Complaints Manager

Tel: 01372 216-202/203/204
Email: rxx.palsandcomplaintssabp@nhs.net

Details can be obtained from http://www.sabp.nhs.uk/contact/PALS

Post: PALS & Complaints Team, Surrey & Borders Partnership NHS Foundation Trust
18, Mole Business Park
Leatherhead
Surrey KT22 7AD

Health & Medicine | Lancaster University

Surrey and Borders Partnership
NHS Foundation Trust

Consent Form (Person with Dementia)

Older People's Mental Health Services

Study Title: Illness Perceptions and help seeking intentions among people with early-stage dementia and their caregivers.

We are asking if you would like to take part in a research project, looking at people's illness beliefs in relation to help seeking intentions when diagnosed with dementia.
Before you consent to participating in the study, we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form, please speak to the principal investigator: **Jane Gregg.**

1.I confirm that I have read the information sheet and fully understand what is expected of me within this study.	
2. I confirm that I have had the opportunity to ask any questions and to have them answered.	
3. I understand that relevant sections of my health and social care notes and data collected during the study, may be looked at by the researcher from Surrey & Borders Partnership NHS Trust, and give permission for the researcher to access my records.	
4. I understand that my questionnaires will be given a unique number and will be used to link my data at a later date.	
5.I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	
6.I understand that if I complete these questionnaires I will not be identified by name in any published reports or papers.	
7.I consent to information gathered from the questionnaires being used in reports, conferences, and training events.	
8.I understand that the researcher will discuss data with their supervisor as needed.	
9.I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor.	
10.I agree if during this research visit, I get distressed I give permission for the researcher to notify my clinician or GP.	
11. I consent to take part in the above study.	

Name of Participant___________________ Signature_____________________ Date ______

Name of Researcher ___________________Signature _____________________Date _______

Appendix 3

Surrey and Borders Partnership
NHS Foundation Trust

Older People's Mental Health Services

Participant Information Sheet (Caregiver)

Study Title***:*** **Illness Perceptions and help seeking intentions among people with early-stage dementia and their caregivers.**

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Jane Gregg and I am conducting this research as a PhD student within the Division of Health Research (DHR,) Mental Health Programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is looking at the association between people's illness beliefs of dementia, and how these impacts on their intention to seek help. This information will be collected by a survey.

Why have I been approached?

You have been approached because the study requires information from people who care for someone with dementia (a caregiver could be a family member or a friend).

Do I have to take part?

No. It's completely up to you to decide whether you take part. Participation in the study is entirely separate from any health or social care you receive and will not affect your day to day care. If you decide not to take part, at any time, your decision will in no way compromise your rights and the standard of care you will receive.

What will I be asked to do if I take part?

The person that you care for must also agree to participate with you. If you both choose to take part in the study a researcher will visit you both and ask you to complete some questionnaires about your health and wellbeing. Questionnaires may be completed electronically or by paper. It is expected that this will take no more than 45 minutes in total. If you require any help, the researcher will be able to assist you complete the questionnaires during this time.

Will my data be Identifiable?

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There are some limits to confidentiality: if anything reported makes me think that you, or someone else, is at significant risk of harm, I will need to break confidentiality and speak to a member of staff who may inform your GP. If possible, I will inform you if I need to do this.

What will happen to the results?

The results will be summarised and reported: in a dissertation/thesis and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

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Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:
Jane Gregg e-mail: j.gregg@lancaster.ac.uk

Project Supervisors: Dr Guillermo Perez Algorta: e-mail: g.perezlgorta@lancaster.ac.uk

Dr Jane Simpson. E-mail: j.simpson2@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Director of Studies:
Dr Sean Hughes Tel: (01524) 510847
Email: Sean.Hughes@lancaster.ac.uk
Division of Health Research
Lancaster University
Lancaster
LA1 4YW

If you wish to speak to someone outside of the PhD DHR Mental Health Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746

Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster LA1 4YG

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Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

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Tel: 0300 222 1122
Email: enquries@alzheimers.org.uk
Web: alzheimers.org.uk

Adult Social Care information and advice line (Surrey County Council)
Tel: 0300 200 1005
Email: contact.centre@surreycc.gov.uk
Web: www.surreycc.gov.uk/adultsocialcare

Advocacy Services:
Tel: 0800 3357330 (Freephone).
Email: info@advocacyinsurrey.org.uk

Patient Advice & Liaison Service (PALS) Complaints Manager
Tel: 01372 216202/203/204
Email: rxx.palsandcomplaintssabp@nhs.net
Details can be obtained from http://www.sabp.nhs.uk/contact/PALS

Post: PALS and Complaints Team. Surrey & Borders Partnership NHS Foundation Trust,
18, Mole Business Park,
Leatherhead KT22 7AD.

Consent Form (Caregiver)

Study Title: Illness Perceptions and help seeking intentions among people with early-stage dementia and their caregivers.

We are asking if you would like to take part in a research project, looking at people's illness beliefs in relation to help seeking intentions when diagnosed with dementia.
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7.I understand that the researcher will discuss data with their supervisor as needed.	
8.I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor.	
9. I consent to take part in the above study.	

Name of Participant___________________ **Signature**_____________________ **Date** ______

Name of Researcher ___________________**Signature** _____________________**Date** _______

Appendix 4

PERSON WITH DEMENTIA BOOKLET

Study ID……………….. Date……………………..

Survey for Person with Dementia

First, please can you tell us a little about yourself?

Q1 What is your age?

____

Q2 What is your gender?

○ Male

○ Female

Q3 Which of the following best describes your ethnic origin?

☐ White

☐ Black or Black British

☐ Irish

☐ Asian or Asian British

☐ Mixed Race

☐ Other ____

Q4 Which statement best describes your current employment status?

- ○ Working (paid employee)
- ○ Working (self-employed)
- ○ Not working (temporary layoff from a job)
- ○ Not working (looking for work)
- ○ Not working (retired)
- ○ Not working due to disability
- ○ Not working (other) ________________________________
- ○ Prefer not to answer

Q5 What is the highest level of school you have completed or the highest degree you have received?

○ No schooling

○ "O" levels/GCSE

○ "A" level

○ Vocational qualifications

○ Bachelor's degree

○ Master's degree

○ Doctoral degree (e.g.PhD)

○ Professional degree (e.g.MD)

Q6. Relationship status:

○ Spouse/Partner

○ Daughter

○ Son

○ Sibling

○ Friend

Q 7. Type of dementia:

○ Alzheimer's

○ Vascular dementia

○ Frontal temporal

○ Lewy Body

○ Mixed

Q 8. Onset of dementia:

○ Early

○ Late

Q 9. Family history of dementia:

○ Yes

○ No

Q 10. Have you ever been diagnosed with any of the following conditions?

- ○ Cancer
- ○ Stroke
- ○ Arthritis
- ○ Asthma/breathing problems
- ○ Osteoporosis
- ○ Bowel/Bladder problems
- ○ Heart disease
- ○ Diabetes
- ○ Anxiety/Depression
- ○ Thyroid problems

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Study ID…………………... ***Date………………………***

YOUR VIEWS ABOUT YOUR DIAGNOSIS OF DEMENTIA

Listed below are a number of symptoms that you may or may not have experienced since your diagnosis of dementia. Please indicate by circling *Yes* or *No,* whether you have experienced any of these symptoms since your diagnosis, and whether you believe that these symptoms are related to your dementia.

	I have experienced this symptom *since my diagnosis*			**This symptom is *related to my dementia***	
Pain	**Yes**	**No**	________________	**Yes**	**No**
Agitation	**Yes**	**No**	________________	**Yes**	**No**
Nausea	**Yes**	**No**	________________	**Yes**	**No**
Breathlessness	**Yes**	**No**	________________	**Yes**	**No**
Weight Loss or Gain	**Yes**	**No**	________________	**Yes**	**No**
Fatigue	**Yes**	**No**	________________	**Yes**	**No**
Stiff Joints	**Yes**	**No**	________________	**Yes**	**No**
Apathy	**Yes**	**No**	________________	**Yes**	**No**
Depression	**Yes**	**No**	________________	**Yes**	**No**
Headaches	**Yes**	**No**	________________	**Yes**	**No**
Change in appetite	**Yes**	**No**	________________	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	________________	**Yes**	**No**
Dizziness	**Yes**	**No**	________________	**Yes**	**No**
Loss of Strength	**Yes**	**No**	________________	**Yes**	**No**
Anxiety	**Yes**	**No**	________________	**Yes**	**No**
Loss of movement	**Yes**	**No**	________________	**Yes**	**No**
Hallucinations	**Yes**	**No**	________________	**Yes**	**No**
Delusions	**Yes**	**No**	________________	**Yes**	**No**
Memory loss	**Yes**	**No**	________________	**Yes**	**No**
Aggression	**Yes**	**No**	________________	**Yes**	**No**

We are interested in your own personal views of how you now see your current diagnosis of dementia.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR DEMENTIA	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	**My dementia will last a short time**					
IP2	**My dementia is likely to be permanent rather than temporary**					
IP3	**My dementia will last for a long time**					
IP4	**This dementia will pass quickly**					
IP5	**I expect to have dementia for the rest of my life**					
IP6	**My dementia is a serious condition**					
IP7	**My dementia has major consequences on my life**					
IP8	**My dementia does not have much effect on my life**					
IP9	**My dementia strongly affects the way others see me**					
IP10	**My dementia has serious financial consequences**					
IP11	**My dementia causes difficulties for those who are close to me**					
IP12	**There is a lot which I can do to control my symptoms** of dementia					
IP13	**What I do can determine whether my dementia gets better or worse**					
IP14	**The course of my dementia depends on me**					
IP15	**Nothing I do will affect my dementia**					
IP16	**I have the power to influence my dementia**					
IP17	**My actions will have no affect on the outcome of my dementia**					
IP18	**My dementia will improve in time**					
IP19	**There is very little that can be done to improve my dementia**					
IP20	**My treatment will be effective in curing my dementia**					
IP21	**The negative effects of my dementia can be prevented (avoided) by my treatment**					
IP22	**My treatment can control my dementia**					
IP23	**There is nothing which can help my dementia**					
IP24	**The symptoms of my dementia are puzzling to me**					

IP25	**My dementia is a mystery to me**					
IP26	**I don't understand my dementia**					
	VIEWS ABOUT YOUR DEMENTIA cont.	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP27	**My dementia doesn't make any sense to me**					
IP28	**I have a clear picture or understanding of my dementia**					
IP29	**The symptoms of my dementia change a great deal from day to day**					
IP30	**My dementia symptoms come and go in cycles**					
IP31	**My dementia is very unpredictable**					
IP32	**I go through cycles in which my dementia gets better and worse.**					
IP33	**I get depressed when I think about my dementia**					
IP34	**When I think about my dementia I get upset**					
IP35	**My dementia makes me feel angry**					
IP36	**My dementia does not worry me**					
IP37	**Having this dementia makes me feel anxious**					
IP38	**My dementia makes me feel afraid**					

CAUSES OF MY DEMENTIA

We are interested in what you consider may have been the cause of your dementia. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your dementia rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your dementia. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	**Stress or worry**					
C2	**Hereditary - it runs in my family**					
C3	**A Germ or virus**					
C4	**Diet or eating habits**					
C5	**Chance or bad luck**					
C6	**Poor medical care in my past**					
C7	**Pollution in the environment**					

C8	**My own behaviour**					
C9	**My mental attitude e.g., thinking about life negatively**					
C10	**Family problems or worries caused my illness**					
C11	**Overwork**					
C12	**My emotional state e.g., feeling down, lonely, anxious, empty**					
C13	**Ageing**					
C14	**Alcohol**					
C15	**Smoking**					
C16	**Accident or injury**					
C17	**My personality**					
C18	**Altered immunity**					
C19	**Obesity**					
C20	**Gender**					
C21	**Diabetes**					
C22	**Brain Injury**					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR dementia. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me: -

1. ____

2. ____

3. ____

GENERAL HELP-SEEKING QUESTIONNAIRE – Original Version (GHSQ)

Study ID………………...
Date……………………..

1. If you were having a personal or emotional problem, how likely is it that you would seek help from the following people?

Please indicate your response by putting a line through the number that best describes your intention to seek help from each help source that is listed.

1 = Extremely Unlikely 3 = Unlikely 5 = Likely 7 = Extremely Likely

a. Intimate partner (e.g., girlfriend, boyfriend, husband, wife, de' facto)	1	2	3	4	5	6	7
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Mental health professional (e.g. psychologist, social worker, counsellor)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Alzheimer's Society)	1	2	3	4	5	6	7
g. Doctor/GP	1	2	3	4	5	6	7
h. Minister or religious leader (e.g. Priest, Rabbi, Chaplain)	1	2	3	4	5	6	7
i. I would not seek help from anyone	1	2	3	4	5	6	7
j. I would seek help from another not listed above (please list in the space provided, (e.g., work colleague. If no, leave blank)_______________________________________	1	2	3	4	5	6	7

2. If you were experiencing suicidal thoughts, how likely is it that you would seek help from the following people?

Please indicate your response by putting a line through the number that best describes your intention to seek help from each help source that is listed.

1 = Extremely Unlikely 3 = Unlikely 5 = Likely 7 = Extremely Likely

a. Intimate partner (e.g., girlfriend, boyfriend, husband, wife, de' facto)	1	2	3	4	5	6	7
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Mental health professional (e.g. psychologist, social worker, counsellor)	1	2	3	4	5	6	7
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i. I would not seek help from anyone	1	2	3	4	5	6	7
j. I would seek help from another not listed above (please list in the space provided, e.g., work colleague. If no, leave blank)______________________________________	1	2	3	4	5	6	7

Hospital Anxiety and Depression Scale (HADS)

Study ID…………….. **Date…………………..**

Instructions: We are aware that emotions play an important part in most illnesses. This questionnaire is designed to help you recognize how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':	**A**
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I feel as if I am slowed down:	**D**
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I still enjoy the things I used to enjoy:	**D**
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like 'butterflies in the stomach':	**A**
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I get a sort of frightened feeling like something awful is about to happen:	**A**
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

I have lost interest in my appearance:	**D**
Definitely	3
I don't take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I can laugh and see the funny side of things:	**D**
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

I feel restless as if I have to be on the move:	**A**
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

Worrying thoughts go through my mind:	**A**
A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

I look forward with enjoyment to things:	**D**
A much as I ever did	0
Rather less than I used to	1
Definitely less than I used to	3
Hardly at all	2

I feel cheerful:	**D**
Not at all	3
Not often	2
Sometimes	1
Most of the time	0

I get sudden feelings of panic:	**A**
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

I can sit at ease and feel relaxed:	**A**
Definitely	0
Usually	1
Not often	2
Not at all	3

I can enjoy a good book or radio or TV programme:	**D**
Often	0
Sometimes	1
Not often	2
Very seldom	3

EQ-5D Questionnaire

Study ☐ ID

Date ☐

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

Self-Care

I have no problems with self-care ☐
I have some problems with washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities*)

I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain / Discomfort

I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety / Depression

I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

Visual Analogue Scale

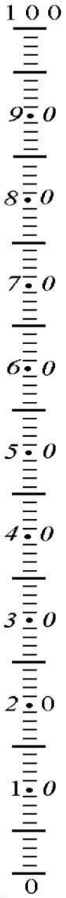
Please indicate on this scale how good or bad your own health state is today.

The best health state you can imagine is marked 100 and the worst health state you can imagine is marked 0.

Please draw a line from the box to the point on the scale that indicates how good or bad your health state is today.

Your own health state today

Best imaginable health state



Worst imaginable health state

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐

Thank you!

Appendix 5

CAREGIVER BOOKLET

ILLNESS PERCEPTIONS AND HELP SEEKING INTENTIONS AMONG PEOPLE WITH EARLY-STAGE DEMENTIA AND THEIR CAREGIVERS

JANE GREGG
LANCASTER UNIVERSITY

Study ID…………………..   Date…………………….

Caregiver Survey

First, please can you tell us a little about yourself and the person you care for?

Q 1. What is your age?

____

Q 2. What is your gender?

○ Male

○ Female

Q 3. Which of the following best describes your ethnic origin?

☐ White

☐ Black or Black British

☐ Irish

☐ Asian or Asian British

☐ Mixed Race

☐ Other ____

Q 4. Which statement best describes your current employment status?

○ Working (paid employee)

○ Working (self-employed)

○ Not working (temporary layoff from a job)

○ Not working (looking for work)

○ Not working (retired)

○ Not working (disabled)

○ Not working (other) ___________________________

○ Prefer not to answer

Q 5. What is the highest level of school you have completed or the highest degree you have received?

- ○ No schooling
- ○ "O" levels/GCSE
- ○ “A” level
- ○ Vocational qualifications
- ○ Bachelor's degree
- ○ Master's degree
- ○ Doctoral degree (e.g. PhD)
- ○ Professional degree (e.g. MD)

Q 6. Relationship status

- ○ Spouse/Partner
- ○ Daughter
- ○ Son
- ○ Sibling
- ○ Friend

Q 7. Type of dementia of your relative/friend

- ○ Alzheimer's
- ○ Vascular dementia
- ○ Frontal temporal
- ○ Lewy Body
- ○ Mixed

Q 8. Onset of dementia of your relative/ friend

- ○ Early
- ○ Late

Q 9. Family history of dementia of your/relative friend

- ○ Yes
- ○ No

Q 10. Have you ever been diagnosed with any of the following conditions?

- ○ Cancer
- ○ Stroke
- ○ Arthritis
- ○ Asthma/breathing problems
- ○ Osteoporosis
- ○ Bowel/Bladder problems
- ○ Heart disease
- ○ Diabetes
- ○ Anxiety/Depression
- ○ Thyroid problems

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Study ID…………………....   *Date*………………………

YOUR VIEWS ABOUT YOUR RELATIVE OR FRIEND'S DIAGNOSIS OF DEMENTIA

Listed below are a number of symptoms that your relative/friend may have experienced since their diagnosis of dementia. Please indicate by circling *Yes* or *No*, whether they have experienced any of these symptoms since their diagnosis, and whether you believe that these symptoms are related to their dementia.

	Have they experienced this symptom *since their diagnosis*?			Is this symptom *related to their dementia?*	
Pain	**Yes**	**No**	________________	**Yes**	**No**
Agitation	**Yes**	**No**	________________	**Yes**	**No**
Nausea	**Yes**	**No**	________________	**Yes**	**No**
Breathlessness	**Yes**	**No**	________________	**Yes**	**No**
Weight Loss or Gain	**Yes**	**No**	________________	**Yes**	**No**
Fatigue	**Yes**	**No**	________________	**Yes**	**No**
Stiff Joints	**Yes**	**No**	________________	**Yes**	**No**
Apathy	**Yes**	**No**	________________	**Yes**	**No**
Depression	**Yes**	**No**	________________	**Yes**	**No**
Headaches	**Yes**	**No**	________________	**Yes**	**No**
Change in appetite	**Yes**	**No**	________________	**Yes**	**No**
Sleep Difficulties	**Yes**	**No**	________________	**Yes**	**No**
Dizziness	**Yes**	**No**	________________	**Yes**	**No**
Loss of Strength	**Yes**	**No**	________________	**Yes**	**No**
Anxiety	**Yes**	**No**	________________	**Yes**	**No**
Loss of movement	**Yes**	**No**	________________	**Yes**	**No**
Hallucinations	**Yes**	**No**	________________	**Yes**	**No**
Delusions	**Yes**	**No**	________________	**Yes**	**No**
Memory loss	**Yes**	**No**	________________	**Yes**	**No**
Aggression	**Yes**	**No**	________________	**Yes**	**No**

We are interested in your own personal views of how you now see your relative/friend's current diagnosis of dementia.

Please indicate how much you agree or disagree with the following statements about your relative/friend's dementia by ticking the appropriate box.

	Views about relative/friend's dementia	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1	**Their dementia will last a short time**					
IP2	**Their dementia is likely to be permanent rather than temporary**					
IP3	**Their dementia will last for a long time**					
IP4	**Their dementia will pass quickly**					
IP5	**I expect them have dementia for the rest of their life**					
IP6	**Dementia is a serious condition**					
IP7	**Dementia has major consequences on my life**					
IP8	**Their dementia does not have much effect on my life**					
IP9	**Their dementia strongly affects the way others see me**					
IP10	**Their dementia has serious financial consequences**					
IP11	**Their dementia causes difficulties for those who are close to me**					
IP12	**There is a lot which I can do to control their symptoms** of dementia					
IP13	**What I do can determine whether their dementia gets better or worse**					
IP14	**The course of their dementia depends on me**					
IP15	**Nothing I do will affect their dementia**					
IP16	**I have the power to influence their dementia**					
IP17	**My actions will have no affect on the outcome of their dementia**					
IP18	**Their dementia will improve in time**					
IP19	**There is very little that can be done to improve their dementia**					
IP20	**Treatment will be effective in curing their dementia**					
IP21	**The negative effects of dementia can be prevented (avoided) by treatment**					
IP22	**Their treatment can control their dementia**					
IP23	**There is nothing which can help their dementia**					
IP24	**The symptoms of their dementia are puzzling to me**					
IP25	**Their dementia is a mystery to me**					

IP26	**I don't understand their dementia**					
	Views about your relative/friend dementia cont.	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
IP27	**The dementia doesn't make any sense to me**					
IP28	**I have a clear picture or understanding of their dementia**					
IP29	**The symptoms of their dementia change a great deal from day to day**					
IP30	**The dementia symptoms come and go in cycles**					
IP31	**The dementia is very unpredictable**					
IP32	**They go through cycles in which their dementia gets better and worse.**					
IP33	**I get depressed when I think about their dementia**					
IP34	**When I think about their dementia I get upset**					
IP35	**Their dementia makes me feel angry**					
IP36	**Their dementia does not worry me**					
IP37	**My relative/friend having dementia makes me feel anxious**					
IP38	**Their dementia makes me feel afraid**					

CAUSES OF RELATIVE/FRIEND'S DEMENTIA

We are interested in what <u>you</u> consider may have been the cause of your relative or friend's dementia. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your relative/friend's dementia rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for their dementia. Please indicate how much you agree or disagree that they were causes for their dementia by ticking the appropriate box.

	POSSIBLE CAUSES	**STRONGLY DISAGREE**	**DISAGREE**	**NEITHER AGREE NOR DISAGREE**	**AGREE**	**STRONGLY AGREE**
C1	**Stress or worry**					
C2	**Hereditary - it runs in the family**					
C3	**A Germ or virus**					
C4	**Diet or eating habits**					
C5	**Chance or bad luck**					
C6	**Poor medical care in the past**					
C7	**Pollution in the environment**					
C8	**Their own behaviour**					

C9	**mental attitude e.g. thinking about life negatively**					
C10	**Family problems or worries caused their illness**					
C11	**Overwork**					
C12	**Emotional state e.g. feeling down, lonely, anxious, empty**					
C13	**Ageing**					
C14	**Alcohol**					
C15	**Smoking**					
C16	**Accident or injury**					
C17	**Personality**					
C18	**Altered immunity**					
C19	**Obesity**					
C20	**Gender**					
C21	**Diabetes**					
C22	**Brain Injury**					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR RELATIVE/FRIEND'S dementia.</u> You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me: -

1____

2____

3____

Study ID………………...
Date……………………...

GENERAL HELP-SEEKING QUESTIONNAIRE- Original Version (GHSQ)

1. If you were having a personal or emotional problem, how likely is it that you would seek help from the following people?

Please indicate your response by putting a line through the number that best describes your intention to seek help from each help source that is listed.

1 = Extremely Unlikely 3 = Unlikely 5 = Likely 7 = Extremely Likely

a. Intimate partner (e.g., girlfriend, boyfriend, husband, wife, de’ facto)	1	2	3	4	5	6	7
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Mental health professional (e.g., psychologist, social worker, counsellor)	1	2	3	4	5	6	7
f. Phone helpline (e.g., Alzheimer’s society)	1	2	3	4	5	6	7
g. Doctor/GP	1	2	3	4	5	6	7
h. Minister or religious leader (e.g., Priest, Rabbi, Chaplain)	1	2	3	4	5	6	7
i. I would not seek help from anyone	1	2	3	4	5	6	7
j. I would seek help from another not listed above (please list in the space provided, (e.g., work colleague. If no, leave blank)______________________________________	1	2	3	4	5	6	7

2. If you were experiencing suicidal thoughts, how likely is it that you would seek help from the following people?

Please indicate your response by putting a line through the number that best describes your intention to seek help from each help source that is listed.

1 = Extremely Unlikely 3 = Unlikely 5 = Likely 7 = Extremely Likely

a. Intimate partner (e.g., girlfriend, boyfriend, husband, wife, de' facto)	1	2	3	4	5	6	7
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Mental health professional (e.g. psychologist, social worker, counsellor)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Alzheimer's Society)	1	2	3	4	5	6	7
g. Doctor/GP	1	2	3	4	5	6	7
h. Minister or religious leader (e.g. Priest, Rabbi, Chaplain)	1	2	3	4	5	6	7
i. I would not seek help from anyone	1	2	3	4	5	6	7
j. I would seek help from another not listed above (please list in the space provided, e.g., work colleague. If no, leave blank)______________________________________	1	2	3	4	5	6	7

Hospital Anxiety and Depression Scale (HADS)

Study ID……………… **Date………………….**

Instructions: We are aware that emotions play an important part in most illnesses. This questionnaire is designed to help you recognize how you feel. Read each item and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or 'wound up':	**A**
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0

I feel as if I am slowed down:	**D**
Nearly all of the time	3
Very often	2
Sometimes	1
Not at all	0

I still enjoy the things I used to enjoy:	**D**
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3

I get a sort of frightened feeling like 'butterflies in the stomach':	**A**
Not at all	0
Occasionally	1
Quite often	2
Very often	3

I get a sort of frightened feeling like something awful is about to happen:	**A**
Very definitely and quite badly	3
Yes, but not too badly	2
A little, but it doesn't worry me	1
Not at all	0

I have lost interest in my appearance:	**D**
Definitely	3
I don't take as much care as I should	2
I may not take quite as much care	1
I take just as much care as ever	0

I can laugh and see the funny side of things:	**D**
As much as I always could	0
Not quite so much now	1
Definitely not so much now	2
Not at all	3

I feel restless as if I have to be on the move:	**A**
Very much indeed	3
Quite a lot	2
Not very much	1
Not at all	0

Worrying thoughts go through my mind:	**A**
A great deal of the time	3
A lot of the time	2
From time to time but not too often	1
Only occasionally	0

I look forward with enjoyment to things:	**D**
A much as I ever did	0
Rather less than I used to	1
Definitely less than I used to	3
Hardly at all	2

I feel cheerful:	**D**
Not at all	3
Not often	2
Sometimes	1
Most of the time	0

I get sudden feelings of panic:	**A**
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0

I can sit at ease and feel relaxed:	**A**
Definitely	0
Usually	1
Not often	2
Not at all	3

I can enjoy a good book or radio or TV programme:	**D**
Often	0
Sometimes	1
Not often	2
Very seldom	3

EQ-5D Questionnaire

Study ☐ ID

Date ☐

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about ☐

I have some problems in walking about ☐

I am confined to bed ☐

Self-Care

I have no problems with self-care ☐
I have some problems with washing or dressing myself ☐
I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities*)

I have no problems with performing my usual activities ☐
I have some problems with performing my usual activities ☐
I am unable to perform my usual activities ☐

Pain / Discomfort

I have no pain or discomfort ☐
I have moderate pain or discomfort ☐
I have extreme pain or discomfort ☐

Anxiety / Depression

I am not anxious or depressed ☐
I am moderately anxious or depressed ☐
I am extremely anxious or depressed ☐

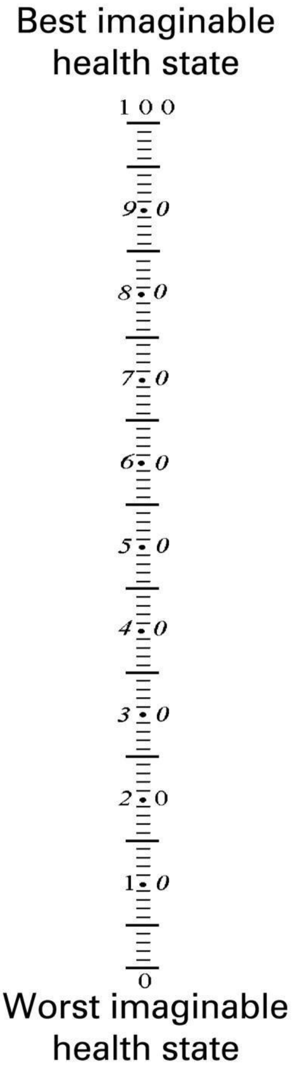
Visual Analogue Scale

Please indicate on this scale how good or bad your own health state is today.

The best health state you can imagine is marked 100 and the worst health state you can imagine is marked 0.

Please draw a line from the box to the point on the scale that indicates how good or bad your health state is today.

Your own health state today



Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐

Thank you!

Appendix 6

Check for updates

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tia

Article

Dementia
2021, Vol. 0(0) 1–21

DOI: 10.1177/1471301221997291
journals.sagepub.com/home/dem
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What is the relationship between people with dementia and their caregiver's illness perceptions post-diagnosis and the impact on help-seeking behaviour? A systematic review

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Abstract

Background: As the number of people with dementia increases, more families will be affected by the daily challenges of providing effective support, given its current incurable status. Once individuals are diagnosed with dementia, the earlier they access support, the more effective the outcome. However, once people receive a diagnosis, how they make sense of their dementia can impact on their help-seeking intentions. Exploring the illness beliefs of people with dementia and their caregivers and this relationship to help seeking may identify how best to facilitate early support.
Aims: To systematically obtain and critically review relevant studies on the relationship between illness perceptions and help seeking of people with dementia and their caregivers.
Method: A systematic search was conducted and included both quantitative and qualitative studies. The initial search was conducted in October 2018. with an adjacent search conducted in April 2020.

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Findings: A total of 14 articles met the inclusion criteria. Conceptually, the studies examined the association of illness perceptions and help-seeking post-diagnosis and revealed that people living with dementia and their caregivers sought help when symptoms became severe. Components of illness perceptions revealed that lack of knowledge, cultural beliefs, complexity of the healthcare system, threat to independence and acceptance were identified as major factors for delaying help seeking.
Conclusion: Although research interest in the area of illness perceptions and their impact on help seeking for dementia is increasing, further work is needed to understand this area, particularly regarding the influence of the relationship between the person with dementia and their caregiver.

Keywords
dementia, Alzheimer's, help seeking, illness perceptions, illness representations

Introduction

Currently, there is no cure for dementia; however, an early diagnosis can bring significant social, personal and economic benefits, which can impact on improving the quality of life for people living with the condition (Perry-Young et al., 2018). Further, seeking out help for interventions, either pharmacological or psychological, at the earlier stages of the disease can be related to milder impairment. For example, a study by Tang et al. (2016) revealed that individuals with dementia who sought help later had worse depressive symptoms and neurological functioning than people who had received treatment earlier. Moreover, a study by Moon et al. (2017) revealed that caregivers reported that the person with dementia was significantly less involved in decision-making for daily support and valued social contact less than their caregiver.

Thus, the notion of accessing treatments for dementia care earlier rather than later is important and is at the core of living well with dementia strategies from governments worldwide (e.g. UK Prime Minister's Challenge on Dementia, 2012). Good post-diagnostic support for people living with dementia and their caregivers can facilitate a better understanding of their condition, as people living with early-stage dementia can potentially plan for their future while still able to do so, enhancing their quality of life (Devoy & Simpson, 2016). However, once people are diagnosed, during the early stages of dementia, they and their caregivers are often reluctant to seek help, as dementia still attracts a level of shame and stigma due to its links with diminished capacity, poorer mental health and loss of independence (Herrmann et al., 2018).

To ameliorate this situation, this review summarises information about the association of illness perceptions with help-seeking intentions, as to provide a framework to understand the components that form an individual's illness perceptions once diagnosed with dementia. The role of illness perceptions has long been acknowledged as an important part in responding to symptom recognition and self-management of diseases or conditions generally (Hagger & Orbell, 2010) and in relation to dementia specifically (e.g. Roberts et al., 2014). There have been several proposed definitions of illness perceptions, comprising different models that include the cognitive and emotional components of a person's representation of their illness. For a more detailed presentation, see Petersen et al. (2011). These processes are important as they can influence an individual's coping strategies once diagnosed, involving risk perception and psychological well-being.

The Self-Regulatory Model (Leventhal & Meyer, 1980) is a useful model for understanding the coping processes and beliefs relating to an illness. This model explains how individuals perceive their illness via cognitive representations, such as identifying with the disease, cause/control, consequences, coherence and the emotional response to the illness (Shinan-Altman & Werner, 2019). Therefore, illness perceptions and their relationship to help seeking are important determinants of the individual's management of their illness. Sometimes, these lay representations will coincide with scientific orthodoxy and sometimes they will be at odds with more accepted beliefs around the condition. Thus, understanding how people make sense of dementia and its implications is an important issue when working with individuals as they come to terms with their dementia diagnosis (Harman & Clare, 2006).

A recent systematic review of help seeking for dementia (Werner et al., 2014) examined non-professional and professional sources of help seeking, with results showing a preference for seeking help from close family members and friends followed by primary healthcare services. However, this review did not explore the mechanisms implicated in the process of help seeking, such as illness perceptions.

While research in the area of help seeking for dementia has been increasing, to the best of our knowledge, there has not been a review exploring how the person with dementia and their caregiver's illness perceptions impact on help-seeking intentions once diagnosed with dementia. Therefore, a clearer understanding of how people's illness perceptions and the relationship to help seeking once diagnosed may provide insight into an individual's attempt to manage the illness. Thus, the aim of this review was to provide a preliminary evaluation of the available literature (qualitative and quantitative) on the relationship between illness perceptions with help seeking with people diagnosed with dementia and their caregivers.

The specific review questions are as follows:

1. How do illness perceptions impact on the intention to seek help after a diagnosis of dementia?
2. How does a caregiver's illness perceptions impact on their intention to seek help for the person with dementia and for themselves?

Methods

Search strategy and selection of studies

The methodology applied for this review was based on the Evidence for Policy and Practice Information and Co-ordinating Centre guidelines (EPPI-Centre; Oliver et al., 2005), which was designed for wide-ranging research questions including both quantitative and qualitative evidence (Clement et al., 2014). The EPPI-Centre incorporates an initial scoping and mapping exercise to specify and prioritise any relevant studies. After conducting a scoping review, this revealed two main types of literature: qualitative and quantitative.

In line with the EPPI-Centre method, a parallel review was conducted for the quantitative and qualitative studies, with findings from both reviews brought together in juxtaposition in a meta-synthesis. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist guidelines for the conduct of the findings were applied (see Figure 1). As this literature review incorporated a broad subject area, a search of general databases was conducted utilising Cochrane Central Register of Controlled Trials, Cochrane Dementia and Cognitive Improvement Group, ALOIS and Centre for Reviews and Dissemination; however, this search did not identify any relevant studies; thereafter, more specific health-related databases were searched. These were Cumulative Index to Nursing and Allied Health Literature, PsycINFO, MEDLINE and PubMed. Furthermore, each individual database was searched with relevant subject headings from February 2018 to August 2018 and revised in October 2018. An adjacent search was conducted in April 2020. Search terms were identified in collaboration with a specialist librarian. The search terms used were dementia or 'vascular dementia' or 'Alzheimer's' or 'Lewy body' or 'frontotemporal' and were

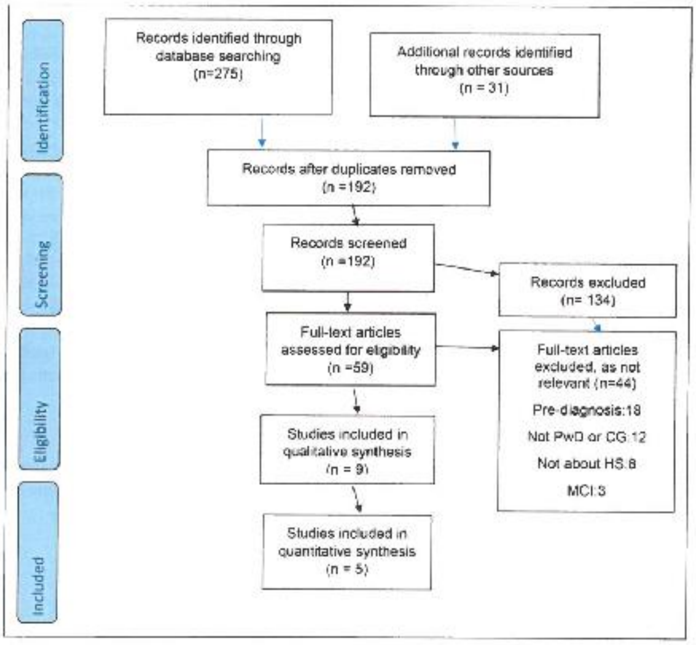

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. MCI: mild cognitive impairment; HS: help seeking, CG: caregiver, PwD: people with dementia.

applied as MeSH terms which produced >94,000 hits. Thereafter, the search was modified with search terms aimed to represent the primary concepts of 'dementia', 'help seeking' and 'illness perceptions'. Keywords entered were 'Illness perceptions and Alzheimer's and help seeking' 'Illness representations or help seeking' 'dementia and caregivers or help seeking or illness perceptions'. Adjacent search terms were 'Identity' or 'control' or 'cause' or 'timeline' or 'consequences' or 'emotion' or 'coherence' and 'dementia' and 'help seeking' The search process was also enhanced by manual searching of reference lists. Experts in the field were also contacted for any ongoing/or unpublished studies. Additionally, grey literature was searched on electronic databases (OpenGrey, BASE). Once articles were identified through this database search, the main reviewer (JG) screened titles and abstracts to assess eligibility.

Inclusion criteria

- Studies that identified key terms in title, abstract or MeSH headings were retained.

- Inclusion criteria were studies that explored relationships between illness perceptions and help-seeking intentions/behaviours for people diagnosed with dementia and their caregivers and receiving informal care in the community.
- The term 'perception' did not have to be applied, as studies looking at these associations can use other terms such as illness 'representations', 'cognitions' or 'beliefs'
- Articles published in peer review journals and written in English.

Quality assessment

Before the quality assessment was conducted, an agreed standardisation of 80% level of agreement was considered acceptable between two reviewers (JG and RN). The second reviewer, RN, is a consultant psychiatrist specialising in dementia. The two reviewers independently assessed the qualitative studies applying the Critical Appraisal Skills Programme (CASP, 2018) checklist assessment tool. The main reviewer (JG) assessed all qualitative studies, with the second reviewer (RN) independently assessing a random sample ($n = 5$) of paper's and clarified inconsistencies with the main reviewer for rigour and suitability for the review. The CASP checklist was designed as a tool within educational workshop settings; thus, a scoring system is not recommended; moreover, this format has been deemed appropriate for assessing qualitative studies (CASP, 2018).

For the quantitative studies, methodological quality was also assessed (JG and RN) by using the cross-sectional survey checklist (Centre for Evidence Based Management, 2014, adapted from Crombie, 1996). The main reviewer (JG) and second reviewer (RN) independently assessed studies using checklist criteria and resolved discrepancies through mutual discussions. Figure 1 details the final selection of studies.

Data extraction strategy

Data from all studies were extracted by the main reviewer (JG) using a data extraction tool adapted from Egan et al. (2003). Standard study characteristics were extracted, plus details of study design, outcome measures and main findings. Using this tool aided in the collating of data from selected articles and helped identify differences and similarities in terms of key findings and methodology.

Data synthesis

Findings were synthesised applying standard methods for narrative synthesis (Popay et al., 2006). Narrative synthesis was utilised as there was a substantial clinical and methodological heterogeneity between all studies. Moreover, a meta-analysis was not deemed appropriate as heterogeneity was considerable across selected studies in respect of primary outcomes, types of dementia and cultural differences. Therefore, the analysis incorporated a compare and contrast approach by conducting a comprehensive juxtaposition of review findings across all identified studies (Popay et al., 2006). Additionally, a tabular presentation of the characteristics of the identified studies was included to support the narrative and to aid in identifying patterns across the data (see Tables A1 and A2 in Appendix A).

Data analysis

Qualitative studies were analysed by the main reviewer (JG), adopting a thematic analysis (Braun & Clarke, 2006). Thematic analysis provides a tool to analyse and identify themes unrestricted from any theoretical undertakings and has been applied successfully when synthesising various data sets, enabling flexibility within various theoretical paradigms (Bunn et al., 2012). Illness perception dimensions were noted by identifying recurring and prominent themes and allowed for categories to emerge from the data. This process allowed for grouping and regrouping of relevant data associated with illness perceptions. Thereafter, data were revised to identify interrelated themes and subthemes across and within the data set to form a final set of emergent themes (Clarke & Braun, 2017).

Quantitative studies were also analysed by the main reviewer. For quantitative studies, values representing the association between perceptions/cognitive processes and help seeking were extracted, and illness perceptions grouped into identity, cure/control, cause, consequences, coherence and emotional representations (Leventhal & Nerenz, 1985). The relationship between illness perception dimensions and reported outcomes was based on an examination of the author's interpretations of data-specific sets that supported the relationship and its direction (Clement et al., 2014).

Findings

Included studies

As noted in Figure 1, a search of databases was completed and yielded 275 references. Thereafter, 31 additional references were identified via other sources. After removal of duplicates and studies that clearly did not meet the inclusion criteria, 192 full text records were retrieved. Of these 192 records, a further 134 were excluded at this point as not being relevant, leaving 59 full text references to be assessed further for eligibility. Of these remaining records, 44 studies were excluded as they did not meet all the inclusion criteria. Therefore, 14 studies were eligible to be included in this review. Nine studies were qualitative and five were quantitative. See Figure 1 for PRISMA flow chart diagram of search process.

Study and participant characteristics

The selected studies were from various backgrounds (psychology, psychiatry, public health, mental health nursing and dementia) and included articles from various countries. In summary, seven studies were US based, two UK based and two Australia based, and there was one study each from China, Hong Kong, Vietnam and Europe (eight European countries in total, including the UK). In relation to study settings, community-based scenarios were day-care units, dementia clinics, support groups and a roadshow. For participants recruited into the studies, 11 studies involved caregivers, with only three investigating people with dementia as well as their caregivers. Regarding the approach applied for data collection for the qualitative studies, four applied semi-structured interviews (Au et al., 2013; Haralambous et al., 2014; Mukadam et al., 2015; Peterson et al., 2016), two focus groups (Braun et al., 1996; Stephan et al., 2018), one an unstructured interview, (Browne et al., 2007), one was descriptive (Braun & Browne, 1998) and one employed a roadshow/discussion format (Parveen et al., 2017). For the five quantitative studies, four applied a survey design (Hinton et al., 2006; Phillipson et al., 2013; Smyth & Milidonis, 1999; Valle et al., 2004) with no follow up and one was a longitudinal survey (Cox, 1999) with two follow up evaluations over a 12-month period.

Quality appraisal: Qualitative studies (n = 9)

The CASP (2018) checklist tool assessed for quality regarding justification for methods used, data source collection and analysis, and all studies were considered appropriate. However, most studies (*n* = 6) did not either report informed consent procedure or confidentiality processes. Moreover, all included studies did not adequately describe the relationship between the researcher and participants, with no reflection on any potential influence regarding collecting and analysing data. Only two studies (Haralambous et al., 2014; Parveen et al., 2017) applied a theoretical framework. Table A3 reports on the methodological issues for all included qualitative studies (see Appendix A).

Quality appraisal: Quantitative studies (n = 5)

By utilising the cross-sectional survey checklist (Crombie, 1996), all studies applied measures that were reliable and valid. Furthermore, the samples utilised in all the studies were representative of the sample by reflecting similar characteristics among the population being researched. Additionally, only one study (Phillipson et al., 2013) reported confidence intervals for main results and only two studies (Cox, 1999; Phillipson et al., 2013) clarified the theoretical framework. Table A4 below outlines the methodological issues for the quantitative studies (see Appendix A).

Emerging themes across all studies

The subthemes identified in the qualitative studies were also apparent in the quantitative studies. By comparing and contrasting findings across all studies, the five following themes were identified. Most frequent rated themes that emerged (>5) are presented in a tabular format in Table A5 (see Appendix A).

Qualitative studies

The synthesis of qualitative studies produced findings relating to the illness perceptions of individuals and their identifying symptoms of dementia and the relationship of these to cultural beliefs and their impact on help seeking (Au et al., 2013; Braun & Browne, 1998; Mukadam et al., 2015; Parveen et al., 2017; Valle et al., 2004). One major theme related to cultural beliefs was the perceived consequence and the acceptance of duty of care from the caregivers (CGs). Seeking help can be construed as a weakness; thus, an unwillingness to seek help can be formed within an individual's own perception of the consequences of caring for someone with dementia. This was noticeable in studies by Braun et al. (1996) and Braun and Browne (1998). They reported that Asian family hierarchal structures (i.e. duty to pay back to elders) influenced how people interrelated within their rule as CGs. CGs' own illness perceptions on the causes of dementia were seen as being attributed to normal ageing and within the family network went unnoticed. Moreover, perceptions of accepting a diagnosis of dementia were highlighted by Braun et al. (1996) and Braun and Browne (1998). These specific cultural beliefs can impact on seeking medical help, whereas CGs would only consider taking a person with dementia to a clinician if dementia symptoms were severe, in the belief that nothing could be done to cure them (Braun et al., 1996, Braun & Brown, 1998).

Secondly, findings revealed that an individual's perception of the breadth of the concept of dementia could be an overwhelming experience for the person with dementia and the CG (Au et al., 2013; Browne et al., 2007; Haramlamblous et al., 2014). This lack of understanding about dementia could exacerbate the development of a coherent illness identity and could impact on an individual's decision not to seek help. Furthermore, the quality of care experienced previously from health professionals could influence an individual's tendency to seek help or not. If individuals had a negative experience, engagement became more difficult and professionals were rebuffed. Negative beliefs about residential and respite care were associated with non-use of these services (Haramlambous et al., 2014; Stephan et al., 2018).

Themes around an individual's perception of the lack of controllability and coherence of dementia and the threat to independence in the context of living with dementia at home were apparent in articles by Stephan et al. (2018) and Peterson et al. (2016). In particular, the study by Stephan et al. (2018) reported that people's attitudes and beliefs towards a diagnosis of dementia could impact on how they accepted the disease and then their subsequent use of formal care. These beliefs were reported as a major hindrance across all of the eight countries included in the article, suggesting that the person with dementia may lack insight into the symptoms associated with the condition and therefore lack awareness of their needs in respect of asking for help.

Quantitative studies

Findings from the three association studies (Phillipson et al., 2013; Smyth & Milidonis, 1999; Valle et al., 2004) produced mixed conclusions. The study by Smyth and Mildonis (1999) reported a positive correlation among normative beliefs, derived from the CG's own standards of caregiving and their relation to help seeking. CGs' perceptions of the coherence of dementia and their own health were not significantly correlated to direct care tasks involving formal help providers, suggesting that help seeking was not influenced by caregivers' own perception of cause and coherence of the severity of dementia symptoms. However, the quota of care tasks involving seeking help from formal helpers was marginally inversely correlated with Belief in Carer Independence (BCI) suggesting a small effect size. Despite the considerable variation of normative beliefs regarding the role of CGs and help seeking, there was a limited association between these beliefs and patterns of help seeking. For example, with BCI associated with carers' feelings of being trapped, but preference for informal care and concern for family opinion was not. This suggests perceptions of the consequences of caring for someone with dementia can affect help seeking.

Valle et al. (2004) reported significant differences in caregiver experiences, with the strength of relationship between ethnic groups (Latino and Euro-American) and help seeking moderately strong (ethnic group factor explained 22% of variance of the dependent variable). Moreover, ethnicity was the only significant variable related to social network help seeking. Despite the strength of these associations between ethnicity and help seeking, the total model only accounted for 20% of variance in social network seeking scores which can be interpreted as a small effect size. Phillipson et al. (2013) used an expanded version of the Anderson Behavioural Model (ABM) (Anderson & Newman, 1973) to identify associated factors (health beliefs, perceived needs and social structures) with non-use of services. The ABM accounted for 42% of the variance in non-use of residential respite care and 67% for non-use of day care. This suggests that negative illness perceptions relating to controllability of the disease and emotional representations of CGs could result in negative outcomes for the person with dementia, as both were strongly associated with non-use. Overall, the model accounted for two-thirds of the variation of non-use of day care in relation to people's perception of community services for dementia which can be interpreted as large effect size.

Cox (1999) and Hinton et al. (2006) investigated frequency distributions and patterns of use of services (i.e. professional help, support groups and day care). Cox's study was the only longitudinal study over 12 months. Findings suggest that frequencies for both groups (African Americans [AA] and white caregivers) who sought support from services were similar (approximately 50% across both groups). The primary reason for seeking help was to obtain information on dementia, suggesting that attempts to create a coherent understanding of the disease facilitated help seeking. However, significantly more of the AA group requested day care than white CGs who enquired about support groups. Hinton's article reported that a high percentage of CGs (80%) had sought help for at least one dementia symptom, with patterns of help seeking demonstrating that CGs reported disclosure of symptoms to the care recipient primary care provider. Furthermore, in Hinton's study (2006), there were high levels of unmet needs for behavioural problems with >68% of CGs expressing a need for emotional support (counseling and information related to dementia). However, there was considerable variation in GG rates discussing neuropsychiatric symptoms with their family doctor, with 57% of GGs disclosing information about inappropriate elation, to 100% disclosing information about hallucinations. This suggests that CGs' perceptions of the identity (symptom profile) of dementia can impact on what kind of help is sought.

Discussion

This review sought to provide a narrative account of how the illness perceptions of people with dementia and their caregivers can impact on their tendency to seek help post-diagnosis. This review presents findings of 14 publications of which nine were qualitative and five were quantitative, with all studies exploring help seeking among people with a diagnosis of dementia living in the community. In contrast to previous reviews that examined the help-seeking intentions of people experiencing symptoms of dementia pre-diagnosis (Perry-Young et al., 2018; Werner et al., 2014), this review focused on help seeking once diagnosed. By synthesising the results from both qualitative and quantitative studies, a general consensus revealed that illness perceptions and the separate components that form these perceptions (symptoms/identity, cure/control, cause, consequences, coherence and emotional representations) were associated with barriers and facilitators to help seeking. These included strong cultural beliefs about symptoms of dementia, associating the disease as part of the ageing process. Also, inadequate knowledge and beliefs about dementia (coherence), and previous experiences of healthcare services (emotional representations and consequences), caused difficulty in identifying the symptoms of dementia and acceptance of a diagnosis (symptoms/cause/control).

Regarding quantitative studies, three of the five selected studies were association studies and, of these, two reported magnitude of effect sizes in relation to help-seeking intentions and an individual's beliefs of dementia. Even though the sample of articles reviewed was small, findings were variable. Studies including frequencies and patterns of help seeking indicated that CGs were forthcoming in asking for help, specifically regarding information seeking. However, they also reported that the emotional burden of caring for someone with dementia could be a barrier for CGs regarding disclosing their own emotional distress for fear of being seen as unable to cope.

These findings were echoed in the qualitative synthesis process, where subthemes of emotional well-being and consequences were identified. These subthemes of emotional well-being, consequences and duty of care demonstrated how illness perceptions in relation to the stigma associated with caregiving may deter help seeking by various means. For example, that people were willing to dismiss the label of receiving formal care, as to avoid the public stigma this attracts, and the desire to avoid internalised feelings of embarrassment and shame (Corrigan, 2004).

Our findings show that individuals' illness perceptions of dementia can contribute to a person's help-seeking behaviour, with this review demonstrating the importance of cultural differences within approaches to help seeking, and how tailored interventions could be beneficial to individuals living away from their country of birth. However, it would also appear that people's perceptions of their understanding of dementia, in relation to accessing health care, can impact on an individual's tendency to seek out help. Also, there were reported instances of delays due to clinicians not identifying CGs' issues of carer burden, and a lack of awareness, knowledge, and trust of dementia services.

A consensus from the studies reviewed is that people living with dementia only seek help when the symptoms start to become more severe. This suggests that an individual's own perception about the severity of dementia can influence the time to seek out help. Barriers to seeking help are lack of knowledge and one's own personal beliefs of dementia symptoms, suggesting that education about seeking help early on for dementia, rather than later, is much needed.

These findings seem to support previous literature on help seeking for dementia (i.e. Perry Young et al., 2018; Werner, 2003; Werner et al., 2014) and suggest that help seeking is a complex process that not only depends on the primary diagnosis but also how the individual makes sense of these changes. These illness perceptions are formed over time, suggesting the intention to seek help is part of a much longer process, as people come to terms with living with dementia (Perry-Young et al., 2018). As diagnostic procedures are becoming more available, it would seem advantageous for primary and community care services to offer interventions post-diagnosis to avoid further crises later (Burns, 2012).

Limitations

A strength of this review is the inclusion of qualitative and quantitative studies, with a broad representative sample. However, we cannot disregard the possibility that some studies may have been missed due to publication bias (significant results more likely to be published). Furthermore, information was synthesised and reported in summary tables with no statistical techniques applied for examination of methodological issues. However, it should be noted that this review was intended to focus on methodological and conceptual developments and the impact on future clinical interventions and research, rather than an exhaustive review of the literature. Although inter-rater reliability was utilised for assessing the quality of studies, the data search, extraction and analysis were conducted by the first author, which may have influenced the identification of criteria used for initial inclusion of studies.

Implications for practice

How people adapt and respond to a diagnosis of dementia is highly determinative of their future care, demonstrating that people's perceptions of living and caring for someone with dementia can be an overwhelming experience. Therefore, it would be beneficial if a collaborative approach between health and social care sectors developed interventions after the initial diagnosis, to engage people who are hard to reach (Aldridge et al., 2019). Engaging people from the outset and supporting them as they adapt to living with dementia may encourage people to have a clearer understanding of the disease. Importantly, findings have shown that there is a delay in seeking help from community services once diagnosed with dementia due to a lack of trust in dementia services and, as people can be referred back to primary care after a diagnosis, a breakdown in communication can occur. After an initial diagnosis, there is little clinicians can offer under community mental health services, suggesting a need for more support at this time point by incorporating a more joined up process at the early stages of diagnosis and subsequent care from the family doctor. Receiving a diagnosis of dementia can be a daunting prospect for the person with dementia and their CG, with people displaying feelings of hopelessness. Thus, an individual's own illness perceptions on dementia can influence their choices and contribute to their help-seeking behaviour.

Conclusion

This review set out to explore and understand how people with dementia and their caregivers seek help after a diagnosis of dementia in relation to their own illness perceptions. In summary, studies in the area of help seeking and dementia have been increasing over the past two decades, indicating a greater interest in an understanding of this concept; however, there remains a gap in the current literature. This review highlighted how the components of illness perceptions and their association with cultural beliefs, lack of knowledge, stigma, acceptance of the condition and experience of services for dementia care can all play part in effecting how people seek out help. However, these processes are formed over time and as people balance their own beliefs and cognitions with the acceptance of living with dementia, the need to seek out help is a long process, rather than occurring at one single time point (Perry-Young et al., 2018). Furthermore, given that stigma can impact on help seeking (Clement et al., 2014), developing strategies to reduce stigma-related issues need to be addressed. A number of interventions do exist, aimed at effecting, for example, societal and individual change (Link & Phelan, 2006). Moreover, only three studies explored the person with dementia's illness perceptions with help seeking, with the relationship between the person with dementia and the CG not considered, suggesting that more research is needed in this area. Therefore, it would seem advantageous for future research to develop interventions addressing the factors highlighted in this review, in respect of the long-term effects of living with dementia in the community.

Authors' Note

This review forms part of the first author's PhD thesis.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

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Appendix A

Table A1. Study characteristics of qualitative studies.

Reference	Objective	Design	Sample	Setting	Analysis	Illness perceptions/ themes	Outcomes
Braun et al. (1996)	To explore perceptions of Vietnamese immigrants in the USA, regarding caregiving and help seeking of a PwD	Focus groups	Four groups. Mean number in groups = 11.5: Men (mean age 65.2) women, (mean age = 55.6) youth (mean age = 23.8) and mixed groups of CG of person with dementia (mean age = 54.0)	Community-Vietnam	Not mentioned	Identity, consequences, control: Duty of care – cultural beliefs	Results reported importance of hierarchy family structures in the Vietnamese population, with a low priority of dealing with dementia when facing problems associated with caring, and a willingness to access services
Braun and Browne (1998)	Presents information on how cultural values and practices affect perception of dementia, caregiving and help seeking	Descriptive	APIs Age not reported	Community-USA	Descriptive	Identity, control, emotional representations: Duty of care – cultural beliefs/ stigma	Cultural beliefs can affect individuals asking for help, this can be seen as a weakness. Family norms dictate the beliefs around responsibility to care for person with dementia

(continued)

Table A1. (continued)

Reference	Objective	Design	Sample	Setting	Analysis	Illness perceptions/ themes	Outcomes
Browne et al. (2007)	To gain an understanding of help seeking process of older husbands CG of wives with dementia	Unstructured interviews	9 CG of persons with dementia mean age = 79 years, range 65–87 years	Community-USA	Grounded theory	Consequences, cure/ control: Complexity of system – negative and positive experiences	Main findings were that attitudes, values, and experiences influenced choices made, especially the influence of negative previous experiences with care providers
Mukadam et al. (2015)	To explore link between attitudes to help seeking for dementia in ME people and the indigenous population	Semi-structured interviews	18 CGs of person with dementia. Mean age = 57 years	Community-UK	Thematic analysis	Identity, cure/ control: Duty of care – cultural beliefs/stigma	All carers seemed to identify early symptoms of dementia, however barriers to early help seeking in the ME population was that a dementia diagnosis was of no use, and that it was a family's duty to care for person with dementia

(continued)

Table A1. (continued)

Reference	Objective	Design	Sample	Setting	Analysis	Illness perceptions/ themes	Outcomes
Au et al. (2013)	To explore coping and help seeking behaviour among Hong Kong CG of PwD	Semi-structured interview	11 CG of persons with dementia. Age range = 43–83 years	Community-Hong Kong	Grounded theory	Emotional representations: Complexity of system – experiences and response from HP	Internal regulation, forbearance and family obligations are linked to not seeking help earlier. Chinese CG may be hesitant about disclosing information and seeking help, as were found to approach family for help rather than HP.
Haralambous et al. (2014)	To determine barriers and enablers to accessing dementia services among older Asian PwD in Melbourne	Semi-structured interview/ cultural exchange model	12 CG of person with dementia mean age of Chinese CG = 54 years Mean age of Vietnamese CG = 62 years	Community-Australia	Cultural exchange odel	Identity, cure/ control: Complexity of system – negative positive experiences	Barriers to accessing services included complexity of health system, language barriers and lack of knowledge about dementia

(continued)

Table A1. (continued)

Reference	Objective	Design	Sample	Setting	Analysis	Illness perceptions/ themes	Outcomes
Peterson et al. (2016)	To understand complex determinants that lead CG of dementia need for education and assess barriers to seeking help	Semi-structured interview	27 persons with dementia and CG. Mean age of CG = 58 years. Mean age of PwD = 79.8 years	Community-USA	Content analysis	Identity, cure/ control/ consequences: Lack of knowledge – symptoms and cause	Barriers to seeking help were linked to knowledge gaps about dementia rather than reluctance to assume CG role. More public education for CGs for person with dementia is needed
Parveen et al. (2017)	To explore perceptions of dementia and use of services among various ethnic community	Roadshows/ discussion groups SRM	175 persons with dementia, carers and community members. Age not reported	Community-UK	Thematic and framework analysis	Identity, cause, emotional representations: Threat to independence – hindrance or help – cultural beliefs	Seeking help from services seen as a hindrance, linked to a lack of awareness about dementia and cultural barriers such as religious beliefs and language
Stephan et al. (2018)	To explore barriers and facilitators to access formal dementia care	Focus groups	147 persons with dementia and CG. Mean age of person with dementia = 76 years. Mean age of CG = 63 years	Community-8 European countries	Content analysis	Identity, cure/ control/ consequences: Lack of knowledge – symptoms and cause	Formal care be a threat to an individual's independence by the PwD. Health professionals seen as key contact

CG: caregiver; API: Asian Pacific Islander; ME: minority ethnic; HP: health professional; SRM: Self-Regulatory Model.

Table A2. Study characteristics of quantitative studies.

Reference	Objective	Design/measures	Sample	Setting	Analysis	Illness perceptions/ themes	Outcomes
Cox (1999)	Exploring experiences of AAs and white CG seeking assistance for person with dementia	Longitudinal/survey/ Anderson Behavioural Model ADL IADL CES-D	300 CGs of person with dementia 150 white CG, mean age = 57 years, 150 AA mean age = 54 years	Community-USA	Chi-square/t-test/ contingency analysis	Cure/control, consequences: Acceptance of diagnosis/ emotional well-being	Both groups showed symptoms of clinical depression. Primary reason for seeking help was to obtain information on dementia. With significantly more AA calling for home help (<.001) or day care ($p < .001$), while more white CG ($p < .05$) called about support groups
Smyth and Milidonis (1999)	Study the relationship between exploration of service use, normative beliefs and help seeking	Survey/psychological scales: CATSI, COO and PIC	120 CG and person with dementia, mean age of CG = 67 years	Community-USA	ANOVA/ correlation	Consequences/ emotional representations: Acceptance of diagnosis/ emotional well-being/ consequences (captivity)	3 subscales significantly correlated: BCI and CFO ($r = .32$, $p < .001$) BCI and PIC ($r = .61$, $p < .001$) CFO and PIC ($r = .22$, $p < .01$). Normative beliefs regarding accessing help were significantly positively associated with CG physical and mental health

(continued)

Table A2. (continued)

Reference	Objective	Design/measures	Sample	Setting	Analysis	Illness perceptions/ themes	Outcomes
Hinton et al. (2006)	To examine dementia neuropsychiatric symptoms severity and help-seeking patterns	Survey/ neuropsychological scales NPI, CES-D and ADL	38 CGs of persons with dementia. Mean age = 70 years	Community-USA	Chi-square	Identity: Complexity of the system – responses from HP, negative & positive experiences	CG perceived unmet needs for professional help in relation to specific NPI symptoms (75% disinhibition, 66.7% delusions). 80% of CG had seeked help for at least one neuropsychiatric symptom
Valle et al. (2004)	Ethnic differences in social network help-seeking strategies	Surveypsychological scales: ASSIS, MBC and WOC-R	89 persons with dementia and CGs. Euro-Americans n = 50, mean age of CG = 69 years. Latino n = 39, mean age of CG = 57 years	Community-USA	Chi-Square/t-test/multiple regression	Cure/control, emotional representations: Duty of care – cultural beliefs	Accounting for 21% variance of social network help seeking, the relationship between ethnicity and help seeking was moderately strong b = −3, p = .04

(continued)

Table A2. (continued)

Reference	Objective	Design/measures	Sample	Setting	Analysis	Illness perceptions/ themes	Outcomes
Phillipson et al. (2013)	Why carers of PwD do not utilise out of home services	Survey/psychological scales: ZBI, ADL and CES-D ABM	152 CGs of persons with dementia. Mean age of CG = 66.36 years	Community- Australia	Univariate analysis/chi-square t-test	Cure/control, emotional representations: Lack of knowledge – symptoms and cause	Beliefs that service use would result in negative outcomes for persons with dementia were strongly associated with non-use of day care (OR 13.11 95% CI (3.75, 45.89) and respite care (OR 6.13 95% CI (2.02, 18.70). ABM accounted for 67-42% variance in non-use of day centres

CATSI: caregiver for attitudes toward services inventory; BCI: Belief in Caregiver Independence; PIC: preference for informal care; CFO: concern for family opinion (Collins et al., 1991); COOs: concern for the opinion of others; ASSIS: Arizona Social Support Interview Schedule (Barno, 2000) MBC: Memory and Behaviour checklist WOC-R: Ways of Coping Revised (Vitaliano et al., 1985); ZBI: Zarit Burden Inventory (Zarit et al., 1998), ADL: activities of daily living; IADL: independent activities of daily living; (Zarit & Zarit, 1987) NPI: Neuropsychiatric Inventory Scale (Cummings et al., 1994); CES-D: Centre for Epidemiological Studies Depression Scale (Radloff, 1977) PwD: person with dementia, CG: caregiver, AA: African American, ABM: Anderson Behavioural Model (Anderson & Newman, 1973), SRM: Self-Regulatory Model (Leventhal & Meyer, 1980).

Table A3. Methodology issues for qualitative studies.

Reference	Design	Methodology issues
Braun et al. (1996)	Focus groups – audio taped	No mention of informed consent
Browne et al. (2007)	Face-to-face unstructured interviews – audio taped	Convenience sampling. Participants recruited through support groups and personal contacts. Possibility for potential bias
Mukadam et al. (2015)	Face-to-face semi-structured interview – audio taped	Purposive sampling. Carers approached by clinician they knew. No mention of informed consent/confidentiality. Participants sent transcripts and invited to comment on accuracy
Au et al. (2013)	Face-to-face semi-structured interview – audio taped	Convenience sampling – no mention of researcher role in study
Haralambous et al. (2014)	Face to face semi-structured interview- audio taped	No mention of informed consent/confidentiality
Stephan et al. (2018)	Focus groups	Sampling procedure – not described adequately, participants contacted by gatekeepers: Support groups and known contact persons from other parts of the project No mention of informed consent/confidentiality

Table A4. Methodology issues for quantitative studies.

Reference	Model	Methodological issues
Cox (1999)	Andersen and Newman (1973)	No CI reported and limitations not reported
Smyth and Milidonis (1999)	Not stated	No CI reported and decision for sample size not reported
Hinton et al. (2006)	Not stated	No CI reported and small sample size (n = 38) in relation to epidemiological standards of Latino American people living with dementia
Valle et al. (2004)	Not stated	No CI reported and cultural issues not taken into consideration
Phillipson et al. (2013)	Andersen and Newman (1973)	Confounding factor of culture not reported

CI: confidence interval.

Table A5. Identified themes in relation to illness perceptions.

Illness perception	Theme	Subtheme
Identity/cure/control	Duty of care	Cultural beliefs/stigma
Cure/control/emotional representations/	Threat to independence	Hindrance or help
Consequences/emotional representations/coherence	Complexity of system	Response from health professional. Negative and positive experiences
Coherence/identity/cause	Lack of knowledge	Symptoms and cause
Identity/cure/control/emotional representations	Acceptance of diagnosis	Emotional well-being/consequences