

Title: 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.

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 health care 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.

Key words: 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 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 et al 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 (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 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:

- 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 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 & 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

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, 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 (Mukadam et al 2011, Au et al 2013, Haralambous 2014, Peterson et al 2016), two focus groups (Braun et al 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 et al 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.

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 2014; Parveen et al

2017) applied a theoretical framework. Table 1 reports on the methodological issues for all included qualitative studies (see appendix 1).

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 1.2 below outlines the methodological issues for the quantitative studies (see appendix 1).

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 1.3 (see appendix 1)

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 2010, Mukadam et al 2011, 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 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 & Haramblous 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. (Haramblous et al 2014, Stephan et al 2016).

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. 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 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 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 (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 CGs who enquired about support groups. Hinton's paper 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 (2011) there were high levels of unmet needs for behavioural problems with >68% of CGs expressing a need for emotional support (counselling and information related to dementia). However, there was considerable variation in GGs 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 a 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 (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 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 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 et al 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 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 2015), 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 to 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.

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Conflict of Interest

None

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Appendix 1

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 2011	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 2013	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 1.2 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.

Table 1.3 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 1:4: 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.

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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 attitudes, 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 the indigenous population	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 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.

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Haralambous 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 yrs Mean age of Vietnamese CG = 62 yrs.	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.
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-Hindrances 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.

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Stephan et al 2018	To explore barriers & facilitators to access formal dementia care	Focus groups	147 persons with dementia & CG. Mean age of person with dementia = 76 yrs. Mean age of CG = 63 yrs.	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.
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Table 1:5: 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 neuropsychiatric symptoms severity and help seeking patterns	Survey/ Neuro Psychological Scales NPI, CES-D & ADL	38 CG of persons with dementia. Mean age = 70 yrs.	Community-USA	Chi- Square	identity: Complexity of the System- Responses from HP, negative a& positive experiences	CG perceived unmet needs for professional help in relation to specific NPI symptoms (75% disinhibition, 66.7% delusions). 80% of CG had sought help for at least one neuropsychiatric symptom.

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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 (Radloff 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).

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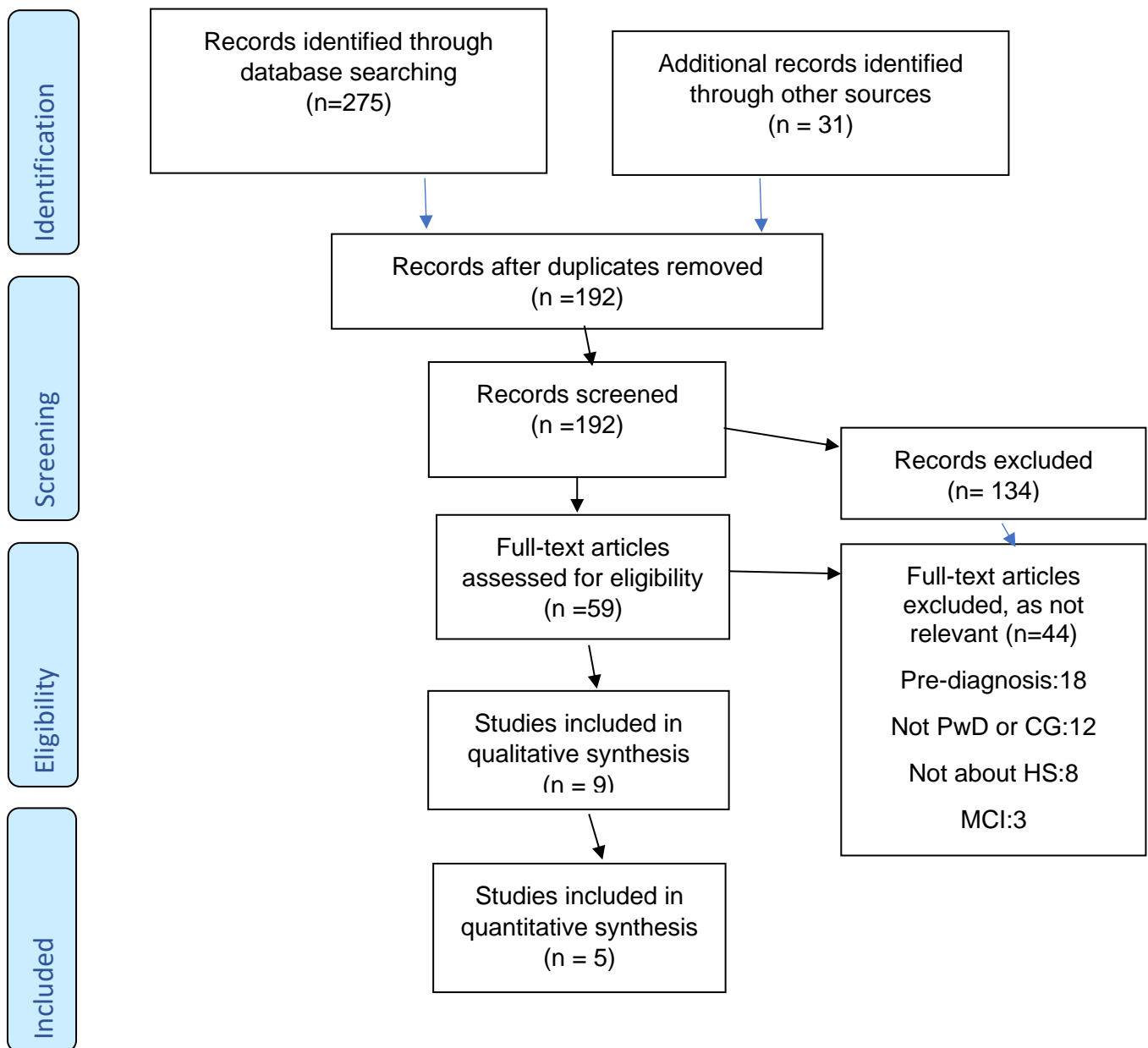


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. MCI = Mild Cognitive Impairment; HS= Help seeking, CG = Caregiver, PwD = People with dementia.