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Title

Understandings of dementia in low and middle income countries and amongst indigenous peoples: a systematic review and qualitative meta-synthesis

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ABSTRACT

Objectives

Dementia is a growing health priority, particularly in less resourced countries and amongst indigenous populations. Understanding cultural meanings ascribed to dementia is an important aspect of policy development and the provision of culturally congruent care and support for people with dementia, their families and the caring professions. This review investigates conceptualizations of dementia amongst indigenous peoples and populations living in low and middle income countries (LMIC), who experience limited diagnosis and formal care for dementia, and how these shape responses to dementia.

Methods

A systematic search was conducted for qualitative studies, reported in English, that focused on the perceptions, attitudes or understandings of dementia in LMIC and amongst indigenous populations. A qualitative analysis and meta-synthesis was carried out.

Findings

Nineteen articles were included in the review following quality assessment. Dementia was rarely conceptualized as a defined, pathological condition characterized by progressive cognitive decline. Rather, notions of dementia existed within conceptualizations of aging, mental illness, traditional cultural beliefs and the trauma of colonization. Responses to dementia were influenced and perpetuated by community and health providers, and cultural norms for caregiving.

Conclusions

There is a need to understand conceptualizations of dementia from the perspective of all stakeholders within a setting, and the dynamic responses that exist between key stakeholders. Community knowledge systems could facilitate understanding about appropriate and acceptable health and community care responses to dementia, and approaches to stigma reduction. Inclusive discussions about dementia are essential if awareness campaigns are to improve the wellbeing of people with dementia and caregivers.

[250 words]

KEYWORDS

Dementia; Older people; Health knowledge, attitudes, practice; Indigenous; Low and middle income countries; literature review

Introduction

Dementia is a growing health priority, particularly in less resourced countries and amongst indigenous populations (Arkles *et al.,* 2010; World Health Organization [WHO] & Alzheimer's Disease International, 2012). The majority (58 per cent) of people with dementia currently reside in countries classified by the World Bank as low and middle income countries (LMIC), and this proportion is likely to increase in the near future (WHO & Alzheimer's Disease International, 2012). Likewise, prevalence studies of dementia in indigenous populations indicate disproportionately higher rates of dementia than those found in non-indigenous populations (Jacklin, Walker & Shawande, 2013; Li *et al.,* 2014, Smith *et al.,* 2008; Warren, Shi, Young, Borenstein & Martiniuk*,* 2015). These populations already experience inequitable access to health services and poor health outcomes.

Conceptualizations of dementia may be embedded within a society's existing cultural and social constructs, rather than within a biomedical framework (Cohen, 1995; Henderson & Traphagan, 2005; Barker, 2009). In Japan, 'boke' is a cultural concept that is characterized by various signs including those typical of Alzheimer's Disease (AD; Traphagan, 2005). The condition of 'boke' refers to when one perceives, or is perceived to be 'spacing out' (Traphagan, 2005, p.147) or disconnected from social interactions. It is a 'moral concept' (Henderson & Traphagan, 2005, p.273) whereby it is one's social responsibility to prevent 'boke' through personal endeavor, with consequent implications for those perceived to be 'boke' and the associated burden they present to others. Here, cognitive decline in older age is deeply embedded within social constructions, rather than pathological.

In contrast, within a biomedical framework, dementia is a condition of the brain characterized by progressive decline in cognitive function that increasingly affects a person's ability to participate in daily life. Assuming that services exist, a diagnosis of dementia facilitates access to the health system including public, private and community health, and social services. Support from the health and social system may include advice and education about dementia management, medication, and support with maintaining social contact and community involvement. Dementia care is evolving as recognition of the harms of institutionalization and complexities of medication for people with dementia increase (Buckley & Salpeter, 2015), and person-centred approaches gain momentum (Fazio, Pace, Flinner & Kallmyer, 2018). However, beliefs around illness and aging, low awareness and knowledge of dementia, and stigma prevent help-seeking for dementia care (Batsch & Mittelman, 2012; Mukadam, Cooper & Livingston, 2011; Werner, Golstein, Karpas, Chan & Lai, 2014) and negatively impact on the human rights of people with dementia (WHO, 2017).

The first global action plan on public health responses to dementia advocates for the prevention of dementia, and the promotion of care and support that enables the wellbeing of people with dementia and caregivers (WHO, 2017, p. 5). The action plan provides the impetus and framework to drive dementia research and policy change globally. However, health system responses for chronic problems associated with aging are slow to evolve, especially in LMIC (WHO, 2015), where high stakes national health priorities compete. In the Pacific Islands, for example, the population aged over 60 years is expected to increase four fold from 2014 to 2050 (United Nations Population Fund Pacific Sub-Regional Office [UNFPA], 2014). Family and community networks traditionally form the core of care of older people but these networks are threatened due to emigration, urbanization and increasingly nuclear families (UNFPA, 2014). However, attention to other health priorities including non-communicable diseases, mental health, and maternal and child health compete with the growing challenges associated with aging. A similar narrative is true for other lower resourced countries. Indigenous populations also experience significant health disparities, often despite residing in high income countries. Health system responses for indigenous populations should center on culturally congruent provision of care which traditionally entails consideration of cultural approaches to wellbeing and caring (Arkles *et al.,* 2010). There is now recognition of the need to understand issues of dementia in indigenous populations and cross national research is needed to inform policy development (Flicker & Logiudice, 2015).

A key action area of the global action plan on dementia focuses on increasing dementia awareness to foster acceptance and understanding, thereby improving the environment and communities in which people with dementia and caregivers live (WHO, 2017). Understanding conceptualizations of dementia is therefore an important aspect of policy development and provision of culturally congruent care and support for people with dementia, their family and the caring professions. The literature on the perceptions and beliefs around dementia and their impact on experiences for immigrant ethnic minority groups is substantial (Kenning, Daker-White, Blakemore, Panagioti & Waheed, 2017; Mukadam *et al.,* 2011; Sayegh & Knight, 2012). However, synthesis of the literature on perceptions and beliefs around dementia and their impacts in the contexts of lower resourced countries or indigenous populations is currently missing. This review aims to investigate the conceptualizations of dementia amongst indigenous populations and populations living in LMIC, both groups who experience relatively low formal dementia care and support relative to higher income countries and non-indigenous populations, and how these shape responses to dementia.

Methods

Search strategy

A systematic review of empirical literature available online was undertaken to December 2018 (there was no lower date limit applied on the bibliographic databases). The search strategy aimed to capture the following inclusion criteria: study design includes perceptions, attitudes or understandings of dementia; set in LMIC according to the World Bank (2017; High Income Country included if about indigenous population); about indigenous population; empirical; and reported in English. A librarian from the authors' institution educated the first author about the databases that should be used for this specific search and how to search each database comprehensively (Scopus, Medline, PsychINFO, CINAHL and Informit databases), and assisted in developing the initial search strategy. Formation of the search strategy was an iterative process involving several cycles of searching. Search terms were first identified based on the aim of the review and consisted of terms in the categories of 'knowledge, beliefs, attitudes', 'dementia', 'low and middle income countries' and 'indigenous'. Subsequent searches were modified based on keywords in relevant articles of the preceding search. This cycle was repeated several times within a database and then across databases until new terms no longer emerged from the results. Two searches were then performed in each database: one focused on LMIC and the other on indigenous studies. Subject heading terms were used in Medline and CINAHL, and keywords were used in Scopus, PsychInfo and Informit databases. The final searches were set to send updates of new results to the first author. A full description of the final search strategy may be found in Supplementary Appendix A1. Reference lists of articles chosen for further review were also hand searched for other potentially relevant articles.

Review strategy

The review was conducted in several stages (Figure 1). All articles resulting from the search were imported to EndNote (Clarivate Analytics). Duplicate records were removed. Titles and abstracts were reviewed for potential relevance for the aim of the review. Remaining publications were reviewed in full and screened according to the inclusion criteria. Articles were excluded for the following reasons: review article; non-empirical; quantitative methodology, research based in high income country according to the World Bank (2017); evaluation of health service or education intervention; mental illness in general; about dementia experiences with no investigation of perceptions of dementia; or focus purely on younger onset dementia (as social, health and care issues differ and warrant a separate review).

The remaining studies were examined using a data extraction template. Information extracted was study aims, study design, participant recruitment, data collection method, analysis, sample and findings relevant to the review's aim. Quality of reporting in studies was assessed through four criteria and used as a basis for decisions about inclusion or exclusion from the review. The criteria required assessment of reporting quality (as satisfactory or unsatisfactory) for the research question and study design, participant selection, data collection methodology, and data analysis methodology (Table 1; Carroll, Booth and Lloyd-Jones, 2012). Studies that met at least two of the four criteria were included in the review (Supplementary Appendix A2). Carroll and others (2012) suggested that studies assessed to be adequately reported contributed to rich thematic synthesis whereas inadequately reported studies could be excluded from the final synthesis without consequence. Reflexivity, evaluative rigor and study relevance were also assessed, summarized and considered in the context of the review findings and limitations (Supplementary Appendix A2).

[Table 1]

Qualitative analysis and synthesis

The qualitative synthesis used techniques for meta-ethnography (Noblit & Hare, 1988) as they offered a structured and rigorous approach to the review. Initially, studies were grouped according to the country setting or indigenous group and analyzed in these clusters. As studies were read, concepts were identified from the findings of each study. The authors' words were used as much as possible as a strategy to stay true to the original study and maintain context. Through repeated reading of the studies and constant comparison, key concepts emerged that described how the studies were related. Once these key concepts were identified, studies were re-read multiple times to aid in context specific interpretation of study findings for each concept. This was an iterative process with modification, removal or addition of key concepts and was facilitated by the use of a grid containing the studies and key concepts. These key concepts, or translations, were synthesized to form interpretations of each study. These interpretations were considered and synthesised across all the studies to form second order interpretations. In meta-ethnography, the translation and interpretation of studies may result in a reciprocal, refutational or line-of-argument synthesis (Noblit & Hare, 1988). For this review, the second order interpretations were framed into themes. The first author was primarily responsible for all stages of the review and met regularly with fellow co-authors to discuss the quality and inclusion of studies, analysis and synthesis.

Findings

Following review of the articles resulting from the literature search, 22 publications were identified for appraisal of reporting quality. Three studies were excluded following appraisal due to insufficient reporting (Cohen, 1995; Henderson & Henderson, 2002; Mbelesso *et al.*, 2016). A total of 19 publications were included for qualitative analysis and synthesis.

Fifteen studies were set in LMIC: China (n=3); various areas of India (n=4); Iran (n=3); Mexico (n=1); Pakistan (n=1), South Africa (n=1) and Tanzania (n=2). A further three studies involved First Nations populations in Canada and one involved Aboriginal and Torres Strait Islander populations from Australia (Table 2). The studies explored a combination of perspectives from various key stakeholders with personal experience of dementia (including people with dementia, caregivers and service providers), as well as views of community leaders, older people or general community on dementia and aging (Table 2).

The studies reported various aspects of trustworthiness. Nearly all studies reported approval from appropriate bodies and collection of informed consent. The two studies (Patel & Prince, 2001; Shaji *et al*., 2003) that did not report ethical approval from an institution were early studies from the 10/66 Dementia Research Group. Consent was obtained from participants in both studies though only one study reported a process of informed consent. Both studies were published in reputable journals. Some studies conducted interviews and focus groups in participants' languages however not all of these reported steps taken to increase the dependability of translated transcripts. Member checking and investigator triangulation increased credibility of some studies. Few studies described using audit trails and reflexive practices. The studies from Canada were particularly rigorous due to the decolonizing methodologies employed such as consultation with community leaders on research design and inclusion of First Nation peoples throughout analysis and research dissemination (Hulko *et al.,* 2010; Jacklin, Pace & Warry*,* 2015; Lanting*,* Crossley, Morgan & Cammer, 2011). This review aims to draw out similarities and differences in findings between settings, while acknowledging that transferability of a study's findings across settings is often limited by the ability to interpret and describe contexts in sufficient detail (Finfgeld-Connett, 2010).

The studies were related through six key concepts: i) recognition or interpretation of symptoms and behavioral expressions; ii) causal attributions; iii) dementia associated with stigma; iv) fear; v) knowledge needs; and vi) caring and care expectations. Interpretations for each article were formed around these concepts (interpretations in brief, refer Table 2). These interpretations were synthesized into second-order interpretations. The first author framed the interpretations into four themes and these were discussed with the co-authors: (i) conceptualizations of dementia; (ii) meanings for dementia are associated with stage of illness progression and stigma; (iii) conveying and incorporating information about dementia; and (iv) caregiving and care expectations. Each of these is outlined below.

Conceptualizations of dementia

Commonly, across the various study contexts, dementia was largely unheard of as a distinct condition. In Tanzania, where dementia is a topic of recent times, some caregivers, people with dementia and, faith and traditional healers were not sure what the problem was (Mushi *et al.,* 2014; Hindley *et al.,* 2016). Likewise, in Pakistan and China, memory loss and 'child-like' symptoms of dementia were associated with aging, a minor concern for which help was unnecessary (Dai *et al.,* 2015; Hsiao, Liu, Xu, Huang & Chi*,* 2016; Lian *et al.,* 2017; Qadir, Gulzar, Haqqani & Khalid, 2013). Symptoms of dementia existed within cultural conceptualizations of aging, perhaps explaining the uncertainty for some in describing a problem. Conceptualizations of ‘normal’ aging incorporated illness in China, Tanzania and India (Dai *et al.*, 2015; Mushi *et al.*, 2014; Shaji, Smitha, Lal & Prince, 2003). In contrast, most participants with dementia in Iran attributed dementia as a medical disease, separate from aging, that impacted enormously on their lives by causing forgetfulness (Mazaheri et al., 2013). Other people with dementia in this study described dementia as part of normal aging or resulting from a hard life.

Indeed, various causal beliefs and conceptualizations of dementia existed within the same community and included: stress; hard life; death of loved ones; neglect by family; abuse; loneliness; various physiological diseases; malaria; faking or deliberate misbehavior; weakness; poverty; curses; growing connection with the spiritual world; colonization; witchcraft; and, punishment from ancestors. Detailed exploration of these various beliefs in the context of the study’s setting was not the focus of most studies. It can be seen that some of these beliefs align with known issues of aging, including loneliness, abuse, poverty and neglect, perhaps indicating social conditions commonly experienced by older people in some of the study settings. Most commonly though, a conceptualization of dementia within aging constructs had biomedical origins in settings where associations with aging was the predominant view. In First Nation communities in Saskatchewan however, dementia was traditionally conceptualized within aging constructs that carried a spiritual element.

Traditionally, memory loss was viewed in First Nations communities as becoming closer to the creator and spirit world and was not feared or associated with ‘losing it or something’

(Hulko *et al.,* 2010, p. 329). However, meanings of memory loss changed over time and were now connected with impacts of colonization and 'your dementia' was to be feared (Hulko *et al.,* 2010). It was the consequence of colonization where cultural change such as environmental, dietary and lifestyle changes had occurred. This association between dementia and sociocultural change was also apparent in Lanting and others' (2011) study though conceptualizations of dementia appeared to remain within traditional notions of circularity and aging, rather than as a new illness. A study involving Indigenous Australians in the Kimberley region of Australia, found that dementia was associated with old age, brain changes, head injury and lack of family visits (Smith *et al.,* 2011). However, in depth exploration of these understandings and possible associations with the trauma of colonization were not reported. Conceptualizations of dementia changed over time as First Nations communities incorporated social, political and environmental impacts of historical trauma into meanings of health and illness.

Meanings for dementia are associated with stage of illness progression and stigma

Symptoms and behavioral expressions of dementia were associated with different meanings in some studies, loosely aligning with progressive changes of the condition. Responses to dementia varied according to perception of the symptoms and behavioral expressions. In India, more advanced dementia was viewed as a physiological issue for which nothing could be done, rather than a psychological issue or 'weak nerves' as with earlier stages of dementia (Patel & Prince, 2001). Similarly, disruptive behavior, aggression, delusions and incontinence was associated with madness, with resultant adverse consequences for the person with dementia and their family (Brijnath & Manderson, 2011). This contrasted with the cultural category 'sathiyana' or 'going sixtyish', a condition expected with older age and characterized by memory loss, stubbornness, anger and suspicion that was tolerated by the community.

In China, health providers in a rural town with low experience with dementia, associated dementia with psychotic illness while memory loss was perceived as unimportant (Hsiao *et al.,* 2016). Community members were perceived to accept symptoms commonly observed in the earlier stages of dementia as normal aging, which delayed help seeking, while threatening behavioral expressions were thought to cause them feelings of fear. These responses to dementia were similar for caregivers in Mexico and Iran (Juarez-Cedillo, Jarillo-Soto & Rosas-Carrasco*,* 2014; Navab, Negarandeh & Peyrovi*,* 2013) where negative attitudes were directed towards behavioral symptoms that violated social norms and resulted in social isolation of people with dementia and caregivers. In South Africa, behavioral expressions considered strange or “abnormal” were ascribed to witchcraft, a strong cultural belief in Black South African culture that resulted in ‘witches’ being treated with disrespect and violence (Mkhonto & Hanssen, 2018).

Caregiver and community responses of shame, described in many settings, allude to the presence of stigma associated with dementia. This can be seen in the labelling of earlier stages of dementia with terms associated with aging or childishness and in more advanced dementia with harsh terms similar to those used for mental illness. The former terminology commonly described a state that was better tolerated by the community. The impact of terminology on stigma is well illustrated in China. Popular terminology for AD was discordant with cultural values of caregivers due to its translated meaning that mocked older people (Dai *et al.,* 2015). The terminology has since been officially changed by the government in an effort to reduce stigma associated with cognitive impairment in older people (Dai *et al.,* 2015). Interestingly, in the studies with First Nations participants, dementia was commonly discussed in terms of memory loss and forgetfulness (Hulko *et al.*, 2010; Jacklin *et al.,* 2015) with little reference to behaviors that caregivers commonly report as upsetting in later stages of dementia. Lanting and colleagues (2011) report that participants described similar symptoms to those observed in the majority culture with examples of memory loss, wandering and hoarding given.

The pervading negative attitude of the community caused feelings of humiliation to families and people with dementia (Navab *et al.,* 2013) and fear of community judgement (Lian *et al.,* 2017; Navab *et al.,* 2013; Qadir *et al*., 2013). In order to protect the identity of their loved one in the community and to protect them from humiliation, caregivers withdrew socially (Navab *et al.,* 2013; Mazaheri *et al.,* 2013). In one study, community shunned families and made accusations of neglect where people with dementia resided due to socially unacceptable behavioural expressions displayed by some people with dementia and unpleasant smells associated with incontinence (Shaji *et al.,* 2003). Experience with people with dementia was proposed to reduce stigma (Mkhonto & Hanssen, 2018), though it also created fear of the condition (Navab, Negarandeh & Peyrovi, 2012; Lanting *et al.,* 2011). Perceptions of symptoms and behavioral expressions of dementia, as well as terminology, were important factors in stigmatization of dementia and negative responses from communities.

Conveying and incorporating information about dementia

Overall, knowledge of dementia was valuable for caregivers, health providers and communities. Health providers, people with dementia and caregivers sought or saw need for information and training to support them in caring for people with dementia though a lack of support resources or knowledge of available support was commonly reported (Hsiao *et al.,* 2016; Lian *et al.,* 2017; Narayan *et al.,* 2015; Patel & Prince, 2001; Shaji *et al.,* 2003; Navab *et al.,* 2012; Juarez-Cedillo *et al.,* 2014; Mkhonto & Hanssen, 2018; Mushi *et al.,* 2014; Smith *et al.,* 2011; Hulko *et al.,* 2010; Jacklin *et al.,* 2015). The community had little awareness of dementia and this contributed to fear of dementia (Navab *et al.,* 2012). More experience in managing dementia increased confidence of health providers in conveying information and support to caregivers (Hsiao *et al.,* 2016).

Health providers could influence how dementia was perceived by their patients and the community. The use of a term that was offensive to caregivers may have contributed to stigmatization of MCI and AD (Dai *et al*, 2015). Similarly, fatalistic views of aging and dementia discouraged caregivers from seeking health care (Hsiao et al., 2016; Patel & Prince, 2001). These views could have been reinforced by other formal care system factors such as in India where a diagnosis of dementia could exclude a person with dementia from residential aged care facilities (Patel & Prince, 2001). In India, doctors integrated dementia into the cultural understandings of their patients by promoting biomedical classification over social meanings (Brijnath & Manderson, 2011). Younger women tended to draw on these biomedical explanations for dementia while older people drew on existing meanings of illness and integrated aspects of modern lifestyle. In this setting, service providers also associated symptoms and expressions of dementia with aging to discourage stigma related with mental illness. There was a role for service providers in framing dementia, an important finding given that caregivers desired and sought information from professionals.

Caregiving and cultural expectations

In all settings, family was the primary if not only source of care for people with dementia. Despite significant emotional or financial implications, families persisted with providing care. Families provided care: (i) to preserve the role of the person with dementia in keeping family together and pass on traditional knowledge (Hulko *et al.,* 2010, Smith *et al.,* 2011); (ii) to keep a person with dementia living in the community (Hulko *et al.,* 2010, Jacklin *et al.,* 2015; Smith *et al.,* 2011); (iii) to impress on younger generations the traditional value of caring and how to provide care (Dai *et al.,* 2015, Hulko *et al.,* 2010); (iv) out of duty or affection to family (Narayan *et al.,* 2015; Shaji *et al.,* 2003; Navab *et al.,* 2012); and (v) out of religious obligation and reciprocity (Qadir *et al.,* 2013). Despite the caring intentions of family caregivers, people with dementia in Iran found the caring environment confining (Mazaheri *et al*., 2013). They experienced an unwelcome shift in role from valued provider and advisor to being redundant and dependent on others.

Community perceptions of aging and dementia, together with stigmatizing responses, impacted notably on help-seeking and caregiving as described throughout the preceding sections. Adding to this, the influence of strong cultural expectations of caregiving influenced responses to dementia in some settings. In settings that also described strong values of duty and obligation being linked to caregiving, frustrations of caregiving were reported to result in aggression and violence of caregivers toward people with dementia (Narayan *et al.,* 2015; Qadir *et al.,* 2013). Pressures of providing care that met socially acceptable standards were overwhelming for caregivers and had a detrimental impact on caregivers' health (Qadir *et al.,* 2013; Shaji *et al.,* 2003;). Additionally, support from extended family was sometimes felt to be missing (Shaji *et al*., 2003; Qadir *et al*., 2013), or detrimental for a person with dementia (Shaji *et al.,* 2003). Such negative connotations were not associated with the culture of caregiving in indigenous communities though, as in Pakistan (Qadir *et al.,* 2013), disapproving attitudes towards families who used aged care facilities were noted (Jacklin *et al.,* 2015). Studies from indigenous communities found that caregiving within, and engaged with, family and the community was far more desirable than institutional care for caregivers and service providers (Hulko *et al*., 2010; Jacklin *et al*., 2015; Lanting *et al*., 2011; Smith *et al*., 2011).

Summary

Throughout the studies, dementia was rarely conceptualized as a defined, pathological condition characterized by progressive cognitive decline. Rather, notions of dementia existed within conceptualizations of aging, mental illness, traditional cultural beliefs or the trauma of colonization. These understandings were not always homogenous within the populations studied. Conceptualizations of dementia had a temporal aspect accompanied by different responses to dementia. Understandings of dementia influenced help-seeking behaviors, and family and community responses including the presence of stigma and fear. Furthermore, responses to dementia were encompassed within and influenced by culturally defined norms for caregiving.

Discussion

A synthesis about the perceptions and conceptualizations of dementia amongst indigenous populations and populations living in LMIC has been missing from the literature until now. Indigenous populations and populations living in LMIC experience relatively low formal dementia care and support compared with non-indigenous populations and higher income countries. Understanding how dementia is perceived and conceptualized amongst these populations is a critical first step in comprehending how to foster supportive environments, communities and services that are culturally congruent for people with dementia and their families. Furthermore, in lower resourced settings, sustainable responses to dementia should consider the local context and be sensitive to available resources (Ferri & Jacob, 2017). This review highlights the need to understand conceptualizations of dementia of all stakeholders within a setting, and the dynamic responses that exist between key stakeholders, in approaches to awareness raising and provision of community and health services. It corroborates findings from the ethnic minority literature that have associated social and cultural beliefs, stigma and knowledge with barriers to help-seeking (Mukadam *et al.,* 2011; Werner *et al.,* 2014). This review provides a synthesis that should be useful in countries where the discourse around aging and dementia are just beginning.

Given the various cultural, social and biomedical understandings of dementia present within and across different contexts the way in which dementia is discussed in low awareness settings (that is settings where there is low awareness of dementia as a health condition that one can live well) is important. The ‘Looking out for dementia’ initiative is an educational resource developed by the Alzheimer’s Australia organization in the Northern Territory (Australia) that describes dementia, and strategies for the management and risk minimization of dementia for Aboriginal communities (Taylor, Lindeman, Stothers, Piper & Kuipers, 2012). A qualitative evaluation of the resource, consisting of focus groups, interviews and observations of implementation, found that in this low dementia awareness setting, the resource helped people to identify dementia and change their approach to be more supportive and understanding of symptoms of dementia. The success of the resource was attributed to engagement with community during development and implementation, language awareness and skillful facilitation (Taylor *et al*., 2012). Interestingly, although the development of the DVD in local Aboriginal languages was highly valued and improved engagement, the ability to follow through with discussions in local languages was just as important and allowed for support and alleviation of fears, and importantly a forum to develop a 'health vocabulary' around dementia. Formulating a vocabulary to discuss dementia seems a sensible place to start dialog about dementia. Certainly, there is a risk that awareness campaigns will increase or perpetuate stigma (especially given the lack of evidence-based approaches to stigma reduction; Hermann, 2018) having the opposite effect of what is intended (Cahill, 2019).

Finkelstein, Forbes and Richmond (2012) identified a knowledge system for dementia care in their study in a First Nations community that enabled the provision of culturally appropriate dementia care. In the knowledge system, people with dementia, family care providers, community and health providers were recognized to hold and need knowledge, and these stakeholder groups shifted between states of knowing and not knowing through sharing, or failure to share, knowledge. By drawing on the cultural knowledge and experiences of dementia within the groups, culturally appropriate resources and care strategies were formed within the formal care health system. If the knowledge system could be applied in other settings and include all stakeholders, it could facilitate meaningful dialog around appropriate and acceptable health and community care responses to dementia, and approaches to stigma reduction. Furthermore, it is foreseeable that bringing additional stakeholders into the knowledge system, such as policy makers, would strengthen the development and usefulness of solutions.

Future research

Accessible, rigorous research such as that conducted by Hulko and others (2010) is important for informing approaches to dementia care. From their research, Hulko and others (2010) question the assumption that one will seek help when ill, and propose further investigation into the role of community members in supporting First Nations people with dementia and how this can be supported by health systems. In addition, research involving people with dementia as participants and co-researchers was lacking in the settings explored in this review. People with dementia are important owners of knowledge. As advocated by the human rights and dementia advocacy group Dementia Alliance International (https://www.dementiaallianceinternational.org/) and renowned activist, Kate Swaffer, the expertise of people with dementia is imperative in research if the true experience of its impacts and possible solutions are to be learned (Swaffer, 2014). The value of involving people with dementia in research about them is increasingly recognised with useful recommendations for researchers emerging (Cridland, Phillipson, Brennan-Horley & Swaffer, 2016; Phillipson and Hammond, 2018).

There could also be important approaches to dementia care that could be learned from indigenous communities. In some studies, such as those from the First Nations communities in Canada, dementia was described in terms of memory loss and forgetfulness. Other signs of dementia, including changes in personality, and communication and mobility problems, may go unrecognized in the indigenous population. Differences between ethnic groups in terms of symptoms and behavioral expressions of dementia have been reported although there is conflicting evidence (Salazar, Dwivedi & Royall, 2017; Shah *et al.,* 2005; Watari & Gatz, 2004). To our knowledge, similar studies about indigenous groups are not yet in the peer-reviewed literature. Perhaps symptoms and behavioral expressions of dementia have different meanings or are rarely observed in First Nations people with dementia, or perhaps in First Nations community approaches to elder care limits other behavioral expressions.

Limitations

There were very few qualitative studies exploring understandings of dementia in LMIC and amongst indigenous populations in the peer-reviewed literature. Many of the studies included in this review did not explore understandings of dementia in depth, rather, an overview of common perceptions tended to be reported. The scope of the studies included in the review was limited to peer-reviewed journal articles investigating perceptions of dementia. Such articles represented a very low proportion of low and middle income countries and indigenous populations. The review included two studies from India (Patel & Prince, 2001; Shaji *et al.,* 2003) that were conducted well before global discourse on dementia began in earnest (following WHO's endorsement for dementia to be recognized as a public health priority in the year 2012). With increased advocacy for dementia awareness, and new pathways to diagnosis and strategies for care provision for dementia, it is possible that views have changed in this setting, and also in other settings included in this review. A focus on perceptions of dementia is an important limitation of the review as it may have missed studies investigating care practices for dementia, which may have included sociocultural understandings of aging and dementia. Grey literature could have added valuable insight on this topic however empirical evidence was appropriate to strengthen confidence in the review findings. The exclusion of book chapters is a limitation of the review with important case study research, such as that conducted by Barker (2009) in her study of the 'decrepit elderly' in Niue being excluded from the synthesis.

Another limitation is the method chosen for reporting quality as a basis for inclusion and exclusion of studies. This method was chosen in an effort to include as many studies as possible from lower resourced settings where research capacity is growing. However, this meant that studies that were reported inadequately but were rich in information, most notably studies by Cohen (1995) and Henderson and Henderson (2002), were excluded. Finally, inclusion of studies only published in English may have meant that studies were missed. Additionally, translations to English occurred in several settings and is accompanied by a risk that complexities may have been lost in interpretation and dissemination in English.

Conclusion

The global action plan on public health responses to dementia calls for efforts to increase dementia awareness (WHO, 2017) and this is supported by the findings of this review. Notions of dementia exist within established conceptualizations of aging, mental illness, traditional cultural beliefs and the trauma of colonization. Responses to dementia are influenced and perpetuated by community and health providers, and cultural norms for caregiving. Community knowledge systems could facilitate understanding about appropriate and acceptable health and community care responses to dementia, and approaches to stigma reduction. Given the wide variability of, and context specific conceptualizations of dementia amongst communities, engaged and inclusive discussions about dementia are essential if awareness campaigns are to improve, not reduce, the wellbeing of people with dementia and caregivers.

References

Anderson, I., & Irava, W. (2017). The implications of aging on the health systems of the Pacific Islands: challenges and opportunities. *Health Systems & Reform, 3*(3), 191-202. doi: 10.1080/23288604.2017.1342179.

Arkles, R., Jackson Pulver, L. R., Robertson, H., Draper, B., Chalkley, S., & Broe, G. A. (2010). *Aging, cognition and dementia in Australian Aboriginal and Torres Strait Islander people, a life cycle approach: a literature review*. Retrieved from Western Sydney University website: https://researchdirect.westernsydney.edu.au/islandora/object/uws:34258

Barker, J. C. (2009). Between humans and ghosts: the decrepit elderly in a Polynesian society. In Sokolovsky, J., (ed). *The cultural context of aging: worldwide perspectives 3rd ed.* (pp. 607-621). London: Prager.

Batsch, N. L. & Mittelman, M. S. (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia.* Retrievend from https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf

*Brijnath, B., & Manderson, L. (2011). Appropriation and dementia in India. *Culture, Medicine and Psychiatry*, *35*(4), 501-518. doi: 10.1007/s11013-011-9230-2.

Buckley, J. S., & Salpeter, S. R. (2015). A risk-benefit assessment of dementia medications: Systematic review of the evidence. *Drugs & Aging, 32*(6), 453-467. doi:10.1007/s40266-015-0266-9.

Cahill, S. (2019). WHO's global action plan on the public health response to dementia: Some challenges and opportunities. *Aging & Mental Health*, 1-3. doi:10.1080/13607863.2018.1544213.

Carroll, C., Booth, A., & Lloyd-Jones, M. (2012). Should we exclude inadequately reported studies from qualitative systematic reviews? An evaluation of sensitivity analyses in two case study reviews. *Qualitative Health Research*, *22*(10), 1425-1434. doi: 10.1177/1049732312452937.

Clarivate Analytics. EndNote Version X7. Available online at http://endnote.com.

Cohen, L. (1995). Toward an anthropology of senility: anger, weakness, and Alzheimer's in Banaras, India. *Medical Anthropology Quarterly*, *9*(3) 314-334.

Cridland, E. K., Phillipson, L., Brennan-Horley, C., & Swaffer, K. (2016). Reflections and recommendations for conducting in-depth interviews with people with dementia. *Qualitative Health Research,* e1-17. doi: 10.1177/1049732316637065.

*Dai, B., Mao, Z., Wu, B., Mei, Y. J., Levkoff, S., & Wang, H. (2015). Family caregiver's perception of Alzheimer's disease and caregiving in Chinese culture. *Social Work in Public Health*, *30*(2), 185-196. doi: 10.1080/19371918.2014.969858.

Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist, 58*(1), S10-S19. doi:10.1093/geront/gnx122.

Ferri, C. P., & Jacob, K. S. (2017). Dementia in low-income and middle-income countries: different realities mandate tailored solutions. *PLoS Medicine*, *14*(3), e1002271. doi: 10.1371/journal.pmed.1002271.

Finfgeld-Connett, D. (2010). Generalizability and transferability of meta-synthesis research findings. *Journal of Advanced Nursing, 66*(2), 246-254. doi:10.1111/j.1365-2648.2009.05250.x.

Finkelstein, S. A., Forbes, D. A., & Richmond, C. A. M. (2012). Formal dementia care among first nations in southwestern Ontario. *Canadian Journal on Aging, 31*(3), 257-270. doi: 10.1017/S0714980812000207.

Flicker, L., & Logiudice, D. (2015). What can we learn about dementia from research in indigenous populations? *International Psychogeriatrics, 27*(12), 1957-1958. doi:10.1017/S1041610215001684.

Henderson, J. N., & Henderson, L. C. (2002). Cultural construction of disease: a “supernormal" construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology*, *17*(3), 197-212. doi: 10.1023/A:1021268922685.

Henderson, J. N., & Traphagan, J. W. (2005). Cultural factors in dementia: perspectives from the anthropology of aging. *Alzheimer Disease and Associated Disorders*, *19*(4), 272-274.

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A systematic review of dementia-related stigma research: can we move the stigma dial? *The American Journal of Geriatric Psychiatry, 26*(3), 316-331. doi:10.1016/j.jagp.2017.09.006.

*Hindley, G., Kissima, J., Oates, L. L., Paddick, S-M., Kisoli, A., Brandsma, C., … Dotchin, C. L. (2016). The role of traditional and faith healers in the treatment of dementia in Tanzania and the potential for collaboration with allopathic healthcare services. *Age and Aging*, *46*(1), 130-137. doi: 10.1093/aging/afw167.

*Hsiao, H., Liu, Z., Xu, L., Huang, Y., & Chi, I. (2016). Knowledge, attitudes, and clinical practices for patients with dementia among mental health providers in China: city and town differences. *Gerontology and Geriatrics Education*, *37*(4), 342-358. doi: 10.1080/02701960.2014.990152.

*Hulko, W., Camille, E., Antifeau, E., Arnouse, M., Bachynski, N., & Taylor, D. (2010). Views of First Nation Elders on memory loss and memory care in later life. *Journal of Cross-Cultural Gerontology*, *25*(4), 317-342. doi: 10.1007/s10823-010-9123-9.

Jacklin, K., Walker, J. D., & Shawande, M. (2013). The emergence of dementia as a health concern among First Nations populations in Alberta, Canada. *Canadian Journal of Public Health*, *104*(1), e39-44. doi: 10.17269/cjph.104.3348.

*Jacklin, K., Pace, J. E., & Warry, W. (2015). Informal dementia caregiving among Indigenous communities in Ontario, Canada. *Care Management Journals*, *16*(2), 106-120. doi: 10.1891/1521-0987.16.2.106.

*Juarez-Cedillo, T., Jarillo-Soto, E. C., & Rosas-Carrasco, O. (2014). Social representation of dementia and its influence on the search for early care by family member caregivers.

American Journal of Alzheimer's Disease and Other Dementias, *29*(4), 344-353. doi: 10.1177/1533317513517041.

Kenning, C., Daker-White, C., Blakemore, A., Panagioti, M., & Waheed, W. (2017). Barriers and facilitators in accessing dementia care by ethnic minority groups: a meta-synthesis of qualitative studies. BMC Psychiatry, *17*, 316. doi: 10.1186/s12888-017-1474-0.

*Lanting, S., Crossley, M., Morgan, D., & Cammer, A. (2011). Aboriginal experiences of aging and dementia in a context of sociocultural change: qualitative analysis of key informant group interviews with Aboriginal seniors. *Journal of Cross-Cultural Gerontology*, *26*(1), 103-117. doi: 10.1007/s10823-010-9136-4.

Li, S., Guthridge, S., Aratchige, P., Lowe, M., Wang, Z., Zhao, Y., & Krause, V. (2014). Dementia prevalence and incidence among the Indigenous and non-Indigenous populations of the Northern Territory. *Medical Journal of Australia*, *200*(8), 465-469. doi: 10.5694/mja13.11052.

*Lian, Y., Xiao, L. D., Zeng, F., Wu, W., Wang, Z., & Ren, H. (2017). The experiences of people with dementia and their caregivers in dementia diagnosis. *Journal of Alzheimer's Disease*, *59*, 1203-1211. doi: 10.3233/JAD-170370.

*Mazaheri, M., Eriksson, L. E., Heikkila, K., Nasrabadi, A. N., Ekman, S., & Sunvisson, H. (2013). Experiences of living with dementia: qualitative content analysis of semi-structured interviews. *Journal of Clinical Nursing*, *22*, 3032-3041. doi: 10.1111/jocn.12275.

Mbelesso, P., Faure-Delage, A., Guerchet, M., Bandzouzi-Ndamba, B., Mouanga, A. M., Tabo, A., . . . Nubukpo, P. (2016). Social aspects of dementia in central Africa (Edac survey). *African Journal of Neurological Sciences, 35*(1).

*Mkhonto, F., & Hanssen, I. (2018). When people with dementia are perceived as witches. Consequences for patients and nurse education in South Africa. *Journal of Clinical Nursing*, 2018, *27*, e167-e176. doi: 10.1111/jocn.13909.

Mukadam, N., Cooper, C., & Livingston, G. (2011). A systematic review of ethnicity and pathways to care in dementia. *International Journal of Geriatric Psychiatry*, *26*(1), 12-20. doi: 10.1002/gps.2484.

*Mushi, D., Rongai, A., Paddick, S. M., Dotchin, C., Mtuya, C., & Walker, R. (2014). Social representation and practices related to dementia in Hai District of Tanzania. *BMC Public Health*, *14*, 260-67. doi: 10.1186/1471-2458-14-260.

*Navab, E., Negarandeh, R., & Peyrovi, H. (2012). Lived experiences of Iranian family member caregivers of persons with Alzheimer’s disease: caring as ‘captured in the whirlpool of time’. *Journal of Clinical Nursing*, *21*, 1078-1086. doi: 10.1111/j.1365-2702.2011.03960.x.

*Navab, E., Negarandeh, R., & Peyrovi, H. (2013). Stigma among Iranian family caregivers of patients with Alzheimer’s disease: a hermeneutic study. *Nursing and Health Sciences*, *15*, 201-206. doi: 10.1111/nhs.12017.

*Narayan, S. M., Varghese, M., Hepburn, K., Lewis, M., Paul, I., & Bhimani, R. (2015). Caregiving experiences of family members of persons with dementia in South India. *American Journal of*

Alzheimer's Disease and Other Dementias, *30*(5), 508-516. doi: 10.1177/1533317514567125.

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: synthesizing qualitative studies*. London: Sage Publications.

*Patel, V., & Prince, M. (2001). Aging and mental health in a developing country: who cares? Qualitative studies from Goa, India. *Psychological Medicine*, *31*(1), 29-38. doi: 10.1017/S0033291799003098.

Phillipson, L., & Hammond, A. (2018). More than talking: a scoping review of innovative approaches to qualitative research involving people with dementia. *International Journal of Qualitative Methods*, *17*, 1-13. doi: 10.1177/1609406918782784.

*Qadir, F., Gulzar, W., Haqqani, S., & Khalid, A. (2013). A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. *Care Management Journals*, *14*(4), 230-240. doi: 10.1891/1521-0987.14.4.230.

Salazar, R., Dwivedi, A. K., & Royall, D. R. (2016). Cross-ethnic differences in the severity of neuropsychiatric symptoms in persons with mild cognitive impairment and Alzheimer's Disease. *The Journal of Neuropsychiatry and Clinical Neurosciences*, *29*(1), 13-21. doi: 10.1176/appi.neuropsych.15120423.

Sayegh, P., & Knight, B. G. (2012) Cross-cultural differences in dementia: the Sociocultural Health Belief Model. *International Psychogeriatrics*, *25*(4), 517-530. doi: 10.1017/S104161021200213X.

Shah, A., Ellanchenny, N., & Suh, G. (2005). A comparative study of behavioral and psychological symptoms of dementia in patients with Alzheimer's Disease and vascular dementia referred to psychogeriatric services in Korea and the U.K. *International Psychogeriatrics*, *17*(2), 207-219. doi: 10.1017/S1041610205001468.

*Shaji, K. S., Smitha, K., Lal, K. P., & Prince, M. (2003). Caregivers of people with Alzheimer's disease: a qualitative study from the Indian 10/66 Dementia Research Network. *International Journal of Geriatric Psychiatry*, *18*(1), 1-6. doi: 10.1002/gps.649.

Smith, K., Flicker, L., Lautenschlager, N. T., Almeida, O. P., Atikinson, D., Dwyer, A., & LoGiudice, D. (2008). High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology*, *71*(19), 1470-1473. doi: 10.1212/01.wnl.0000320508.11013.4f.

*Smith, K., Flicker, L., Shadforth, G., Carroll, E., Ralph, N., Atkinson, D., … LoGiudice, D. (2011). 'Gotta be sit down and worked out together': views of Aboriginal caregivers and service providers on ways to improve dementia care for Aboriginal Australians. *Rural & Remote Health*, *11*(2), 1650.

Swaffer, K. (2014) Dementia: stigma, language, and dementia-friendly. *Dementia*, *13*(6), 709-716. doi: 10.1177/1471301214548143.

Taylor, K. A., Lindeman, M. A., Stothers, K., Piper, K., & Kuipers, P. (2012) Intercultural communications in remote Aboriginal Australian communities: what works in dementia education and management?. *Health Sociology Review*, *21*(2), 208-219. doi: 10.5172/hesr.2012.21.2.208.

Traphagan, J. W. (2005). Interpreting senility: cross-cultural perspectives. *Care Management Journals*, *6*(3), 145-150.

United Nations Population Fund Pacific Sub-Regional Office [UNFPA]. (2014). *Population aging in the Pacific Islands: a situation analysis*. Retrieved from UNFPA Pacific Island Countries website: https://pacific.unfpa.org/en/publications/population-ageing-pacific-islands-situation-analysis

Warren, L. A., Shi, Q., Young, K., Borenstein, A., & Martiniuk, A. (2015). Prevalence and incidence of dementia among indigenous populations: a systematic review. *International Psychogeriatrics*, *27*(12), 1959-1970. doi: 10.1017/S1041610215000861.

Watari, K. F., & Gatz, M. (2004) Pathways to care for Alzheimer's Disease among Korean Americans. Cultural Diversity & Ethnic Minority Psychology, *10*(1), 23-38. doi: 10.1037/1099-9809.10.1.23.

Werner, P., Golstein, D., Karpas, D. S., Liliane Chan, C. K., & Lai, C. (2014). Help-seeking for dementia a systematic review of the literature. *Alzheimer Disease and Associated Disorders,* *28*(4), 299-310. doi: 10.1097/WAD.0000000000000065.

World Bank. (2017). Current classifaction by income in XLS format. World Bank. Retrieved from https://datahelpdesk.worldbank.org/knowledgebase/articles/ 906519-world-bank-country-and-lending-groups

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. Retrieved from https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

World Health Organization. (2015). *World report on aging and health.* Retrieved from http://www.who.int/ageing/events/world-report-2015-launch/en/

World Health Organization., & Alzheimer's Disease International. (2012). *Dementia: a public health priority*. Retrieved from https://www.who.int/mental_health/publications/dementia_report_2012/en/

Figure 1. PRISMA diagram for review of search results.

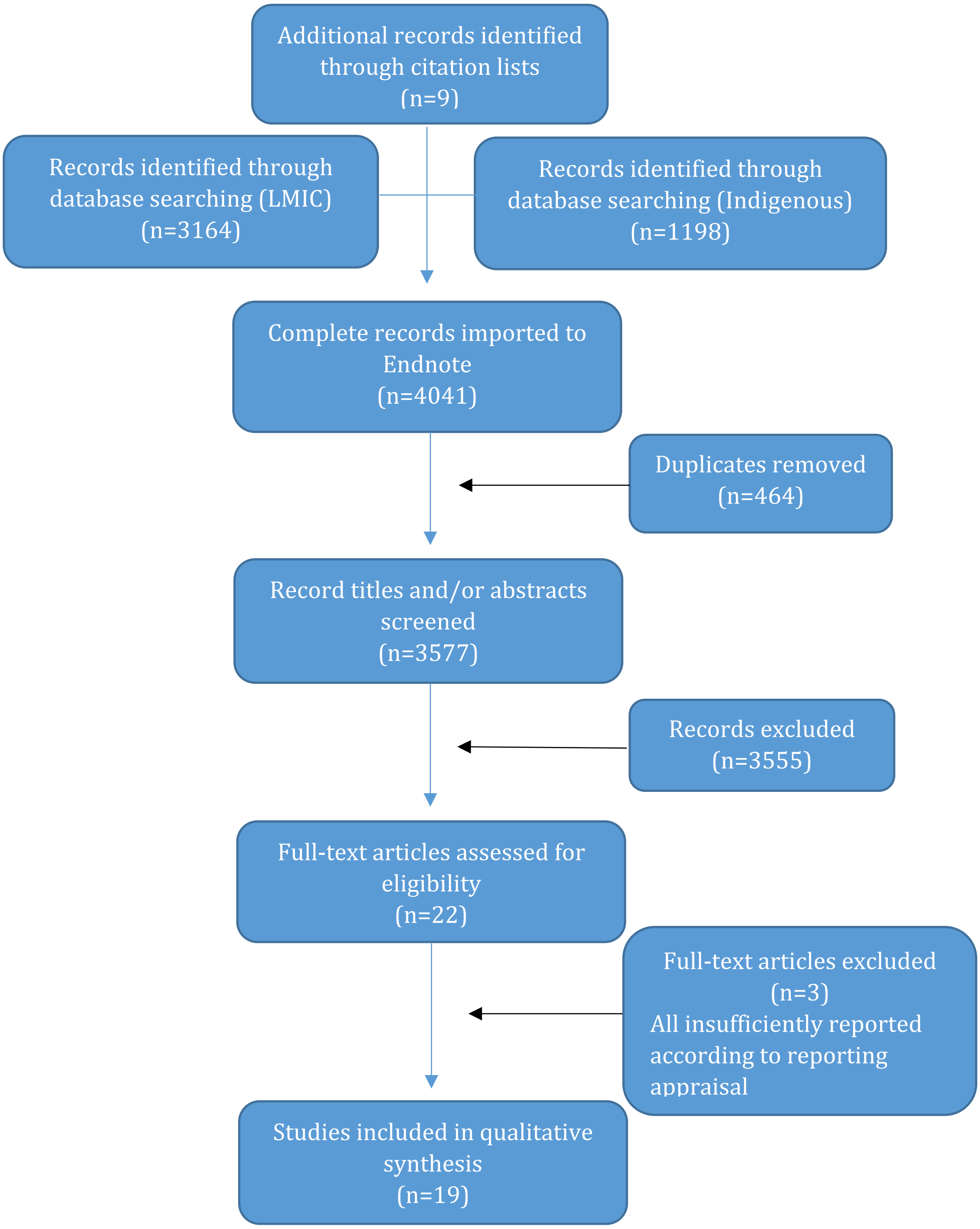

Table 1. Criteria for inclusion of study in review based on quality of reporting (based on Carroll *et al*., 2012).

Criteria	**Rationale**
Question and study design	Research question and study design described
Participant selection	Details provided should include: Sampling method; who, where, how, number recruited
Data collection methodology	Description of formation/piloting of tools, process for data collection, duration, consent
Data analysis methodology	Description of data analysis method. Some specific information should be given about processes used.

Table 2. Studies reviewed for qualitative analysis and meta-synthesis.

Reference and study area	Aims	Study design	Data collection method & analysis	Participants	Interpretations
Brijnath & Manderson (2011) Delhi, India	•Investigate appropriation of dementia diagnosis into meaning and how perceptions of body and self are altered	•Critical ethnography	•Semi-structured interviews Audiotaped; 1 hour duration •Observation in home, hospital, community settings in Delhi and some other cities •Transcribed, thematic analysis with inductive and deductive methods	•Family caregivers of people diagnosed with dementia (n=20); All female, most Hindu, mostly middle-class and some upper class •Key service providers (n=21): health and NGO workers, policy makers, attendants, police	•Responses to dementia from community and caregivers differed according to the severity of the symptoms and more advanced symptoms were associated with stigma. Doctors and service providers frame dementia for patients.
Dai et al. (2015) Wuhan & Beijing, China	•Investigate perception of Alzheimer's Disease and caregiving among caregivers of people with mild cognitive impairment and Alzheimer's Disease	•Grounded theory methods	•Semi-structured interviews Conducted by 2 trained interviewers; Audiotaped; 60-180 minutes •Transcribed into Mandarin Chinese then compared with recording. Also transcribed to English and back-translated. •"Core variables" (described in more than 60% interviews)	•Caregivers of people with diagnosed cognitive impairment: spouses, children, sibling (n=46) •Zhongnan Hospital, Wuhan (n=21); Peking University Dementia Care and Research Centre (n=25)	•Family caregiving and respect for older people is deeply embedded in Chinese tradition and terminology is important - 'laonian chidae' is perceived as offensive. An expectation that illness and dementia are normal for aging people creates a perception that health care is not necessary.
Hindley et al (2016) Hai District, Tanzania	•Explore practice and attitudes to dementia of traditional and faith healers, people with dementia and caregivers	•Qualitative	•Data collection between March - May 2015 •Semi-structured interviews Conducted by 2 researchers in English and Swahili; Audiotaped •Translated to English	•11 traditional healers (all Muslim) •10 faith healers (all Christian) •18 people with dementia and 17 caregivers (family or friends)	•Traditional and faith healers recognize symptoms associated with dementia however not interpreted as collection of symptoms. Caregivers perceive various causes though are unable to articulate a problem. Beliefs about abilities of healers to help with a problem influence help-seeking.

Reference and study area	Aims	Study design	Data collection method & analysis	Participants	Interpretations
Hsiao et at (2016) Beijing, China	•Compare knowledge and attitudes of dementia and practices among mental health providers in city versus town settings	• Qualitative	•Focus group discussions Conducted by 2 researchers; 90 minutes in duration; Video recorded and transcribed •4 researchers conducted the analysis •Framework analysis •Analysis included district, themes, notes	•2 focus groups (n=10/group) per district •Community doctors (n=17; 12 Xicheng) •Hospital physicians (n=11; 2 Xicheng) •Nurses (n=12; 6 Xicheng)	•Health providers with little experience of dementia have misunderstandings of dementia. Implications include poor support for patients and misinformation. Responses from community to dementia are influenced by their perception of the cause of symptoms - normal aging or psychotic illness – delayed help seeking, avoidance and stigma.
Hulko et al (2010) British Columbia, Canada	•Explore perceptions of First Nation peoples on dementia	•Constructivist grounded theory informed by Indigenous perspectives	•3 communities participated •1-2 sharing circles in each community (n=4-9 elders per circle); 1.5-2 hours duration •Interviews similar method; 1.5 hours •Storytelling method; photo elicitation; 3rd party questions •Iterative analysis process; grounded theory methods, collaborative	•Secwepemc Nation people in 43 communities •n=21 Elders; 4 with memory loss; 2 family/ community members •Majority lived on reserve; spoke native language; majority residential schools; majority knew someone with memory loss (probably same person)	•Meanings for memory loss established within trauma of colonization; different to traditional spiritual meanings; Temporal aspect; Supporting one another involves staying within the community with support from the community.
Jacklin et al. (2015) Ottawa, Sudbury, Thunder Bay, Six Nations, Wikwemikong Unceded Indian Research, Manitoulin Island, Mosse Cree First Nation Canada	•Investigate family caregiving for dementia in Indigenous communities	•Qualitative •Critical interpretive approach and participatory approaches	•Semi-structured interviews; Audiotaped; 90 minutes duration Conducted in Indigenous language as appropriate at participant home •Observations; field notes •NVivo to facilitate organization	•Indigenous informal caregivers of people with dementia (n=34); adult children, spouses, extended family, friends •Most caregivers members of immediate family	•Later symptoms of dementia trigger realization of a problem. Traditional Indigenous values of family motivated caring by family though obligation was sometimes a factor. Care is best provided within the community in familiar surroundings and surrounded by family and community. Care homes mostly viewed to not provide culturally appropriate services and contradict strong family caregiving values.

Reference and study area	Aims	Study design	Data collection method & analysis	Participants	Interpretations
Juarez-Cedillo et al. (2014) Mexico city, Mexico	•Investigate caregivers' social representations of dementia and its influences on help seeking	•Qualitative	•Semi-structured interviews in home; 45-60 minutes duration •Approximately March 2010 •Statement semiotics and thematic analysis	•8 primary caregivers of people with dementia aged over 60. All female; most daughters	•Temporal aspect in interpretation of earlier versus later symptoms of dementia; stigma of a mental illness with responses from caregivers of denial, normalization and avoidance which results in restrictions on social environment.
Lanting et al. (2011) Saskatchewan, Canada	•Investigate Aboriginal perceptions of aging and dementia for development of assessment procedures	•Constructivist grounded theory •Participatory	•Small group semi-structured interviews, monthly for six months; 3 hour duration •Researchers active participants – conducted in English with spontaneous use of own language •Shared food	•Aboriginal seniors (n=3) – six key informant group interviews monthly •Reflect diverse backgrounds of Aboriginal groups in town. •All rural background	•Dementia symptoms were associated with normal aging and the 'circle of life' (a cultural concept); linked with post-colonial changes, and evoked fear. Loss of traditional lifestyle contributes to a loss of family and community caregiving.
Lian et al (2017) Chongqing, China	•Investigate experiences of engaging in dementia diagnosis	•Interpretative informed by Gadamer's hermeneutic principles	•Focus group discussions; Audotaped; FG 120 minutes; Interview 30-45 minutes •Collected over 3 months in 2016 •Two researchers conducted FG •Thematic analysis	•1 focus group (n=14) •9 individual interviews •3 people with dementia; rest caregivers	•Responses to dementia are influenced by community perceptions/social networks despite recognition of symptoms of dementia by caregivers. Structural factors also delay help-seeking (financial resources, availability of appropriate service). Education can 'spare' others from stressful experience of late diagnosis.
Mazaheri et al. (2013) Iran	•Describe the experiences of living with dementia in Iran	•Qualitative	•Collected in 2008-2009 •Interviews; Audiotaped; 23-51 minutes in duration •Content analysis	•15 people with moderate dementia (6 female) •3 living alone and close to children; 3 living with spouse and children, 2 living with children; 7 living with spouse	•Dementia a disease that was 'troublesome' and defined by 'forgetfulness'. Responses from others mean that people with dementia are unwillingly relieved of decision-making, responsibility, independence, sharing of knowledge, advice and skills.

Reference and study area	Aims	Study design	Data collection method & analysis	Participants	Interpretations
Mkhonto & Hanssen (2018) Tshwane, South Africa,	•Explore the link between culture and dementia care	•Qualitative	•Narrative interview approach •5 interviewers; 13-63 minutes duration •Hermeneutic approach to theme development	•18 family members (2 Black African background) •19 nurses (18 women)	•Dementia is a white person's disease while viewed as witchcraft in Black South Africans – cultural concept that evokes fear. Education and exposure to people with dementia may be a way to approach beliefs about witchcraft and dementia.
Mushi et al. (2014) Hai District, Tanzania	•Explore socio-cultural beliefs of dementia and experiences of dementia	•Qualitative	•Semi-structured interviews conducted at home; Audiotaped; 45 minutes duration •In Kiswahili language; transcribed and translated to English •Content analysis	•N=25 pairs of caregivers and people with dementia •N=16 caregivers •Most Chagga; followed by Christian; and Muslim •All people with dementia were farmers and most with no primary education	•Dementia recognised and normal part (illness) of aging and not associated with stigma. Various causal attributions. People with dementia require resources to help them maintain their independence while caregivers require education and practical help with care.
Narayan et al. (2015) Bangalore, India	•Investigate extent that meaning and caregiving same across cultures for Indian context SAAVY Caregiver Program	Qualitative	•Semi-structured interviews; Audiotaped •Transcripts translated to English •Conducted in appropriate language •Constant comparative analysis	•Caregivers of people diagnosed with dementia (n=30): most female; most live with care recipient; most middle or low income; most reside in urban areas	•Progressive deterioration of dementia is not well understood by caregivers –symptoms of memory loss and forgetfulness describe the condition hinting at other understandings of later symptoms/expressions of dementia. Multiple causal beliefs. A lack of prior understanding of dementia leaves caregivers extremely unprepared and with caregiving grounded in duty to family and/or God, overwhelmed perhaps contributing to high caregiver stress, poor coping and aggression to person with dementia.

Reference and study area	Aims	Study design	Data collection method & analysis	Participants	Interpretations
Navab et al. (2013) Iran	• To report on family stigma among caregivers of people with dementia in Iran	• Hermeneutic phenomeno-logical approach	• Semi-structured interviews; 63-115 minutes duration • Conducted in Persian (language of all involved) • Collaborative analysis with preliminary findings	• 10 caregivers (8 female) • 13 interviews – 3 people were interviewed twice	• Behavioral symptoms of dementia cause families to feel ashamed and humiliated driving caregivers to socially isolate themselves and their loved one. Caregivers want to protect the identity of their loved one in the community and protect them from humiliation, and fear the effect of community judgement on themselves and their family.
Navab et al. (2012) Tehran, Iran	• Investigate experiences of family caregivers of people with dementia in Iran	• Hermeneutic phenomeno-logical approach	• Semi-structured interviews; 63-115 minutes duration • Conducted in Persian (language of all involved) • Thematic with hermeneutic approach • Collaborative analysis with preliminary findings	• 8 caregivers (7 female) • 11 interviews - some were continued in a separate session	• Caregivers search for cause in their past and meaning; poor knowledge of dementia contributes to fear for a loved one and of the condition.
Patel & Prince (2001) Goa, India	• Investigate understanding of dementia and depression in older age • Investigate views of status, roles and relationships of older people	• Qualitative	• Focus groups using vignettes that describe dementia and depression. • 2 teams (consisting of trained facilitator and observer/recorder) • Audiotaped 45-90 minutes duration • Constant comparison technique • Two researchers coded all separately then compared	• 5 focus groups (FG) with older people (n=37) • 8 FG with key informants (n=51): Councilors, health workers, caregivers • 1 FG of primary care center doctors (n=3); 2 FG with multipurpose health workers (n=17); 1 FG village councilors (n=5); 4 focus groups with caregivers (n=26)	• Temporal aspect in interpretation of earlier and later symptoms. Fatalistic view of dementia associated with construction with aging. Various causal attributions. Recognition of a problem facilitates better care.

Reference and study area	Aims	Study design	Data collection method & analysis	Participants	Interpretations
Qadir et al. (2013) Pakistan	•Investigate perceptions, understanding and impact of dementia in Pakistan	•Qualitative	•Semi-structured interviews in hospital setting •Thematic analysis	•12 primary caregivers (7 female) •All low to middle income •Aged 19-47 •No spouses – all daughters, sons, daughters-in-law, nephew or grandson •Most in nuclear family units rather than joint	•Conceptualizations within aging identified by ‘child-like’ signs. Caregivers responses to dementia are driven by religious obligation and sense of reciprocity rending negligence and expression of distress unacceptable and pressure to keep behaviors hidden from public scrutiny. Shared care between other family members enables care.
Shaji et al. (2003) Kerala, India	•Investigate the experiences of caregivers on dementia.	•Qualitative	•Semi-structured interviews; 30-90 minutes duration. •Detailed field notes – verbatim as much as possible. •Supplemented with information from clinician, nurse and health workers •Constant comparison	•Caregivers (n=17); most females and daughter-in-laws; cared for own young family also.	•Dementia unknown and perceived (not homogenously) to be a disease of aging while other causal attributions place blame on the person exhibiting the symptoms. Caregiving has multiple motivations; duty, family and fate. Knowledge about dementia and its management is important to caregivers, and support from others.. Family pressures and conflict cause reduced well-being for caregivers, and deviation from recommended care.
Smith et al. (2011) Kimberley region; Australia	•Investigate health needs for Aboriginal people living with dementia in remote communities	•Qualitative	•Semi-structured interviews and focus groups; Audiotaped •Caregiver/care staff interviews 30-60 minutes duration •Aboriginal researcher involved in interviewing, transcribing, analysis •Ongoing thematic analysis	•Key service providers (n=42) •Aboriginal caregivers/care staff (n=32) •3 focus groups with community care staff and aged care service providers (number of participants not reported)	•Community and caregivers perceive dementia to have various causes; An older person was valued as a knowledge keeper and important role model who should be cared for within the community, with fear for the wellbeing of those leaving the community for residential aged care. Community want to have knowledge about caring and services, and this could be achieved through genuine community engagement.