

An appraisal of public understanding of dementia across cultures

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Abstract

The 21st century has witnessed a dramatic increase in the population of older adults which can be credited to increasing life expectancy and declining fertility. Although this demographic change has also increased the number of people living with dementia, there are still lots of misconceptions about dementia. This study was aimed at assessing the public understanding of dementia across different cultures. Critical Interpretive Synthesis [CIS] was adopted to review 28 studies on cultural understanding of dementia. Findings showed a generally low awareness of dementia across cultures. The Chinese American immigrants, African-Americans, and Anglo-Europeans understand dementia more from the biomedical perspective. South Asians perceive it to be a result of an individual's actions (Karma), and Chinese and Latino groups consider it as being crazy. The Yoruba tag it insanity while the Pakistanis, Native Americans, Xhosas, and Afrikaners attach religion and spirituality to it. This results in labelling people living with dementia as witches and linking it to the will of God. The misconceptions about dementia affect the attitude of people towards those living with dementia and often leads to delayed diagnosis and treatment. Recommendations such as education, advocacy, and creation of dementia café were made to improve awareness and understanding of dementia.

Keywords: dementia, culture, public understanding, awareness, misconception.

Introduction

The past decade has witnessed a steady increase in the ageing population, leading, naturally, to a reciprocal increase in the number of people living with dementia (World Alzheimer Report, 2015). Dementia can be defined as symptoms that occur when the brain is affected by specific diseases and conditions such as Alzheimer's disease, Creutzfeldt-Jakob disease, and stroke (Alzheimer's Disease International, 2019). These symptoms include memory loss, confusion, speech, and understanding challenges (Alzheimer's Society, cited in Innes, 2009). Although there are different types of dementia, Alzheimer's disease is the most common and accounts for between 50% to 75% of all dementia cases (Denning and Sandilyan, 2015). Other types of dementia include vascular dementia, frontotemporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease dementia, Huntington's disease dementia, and dementia with depression (Denning and Sandilyan).

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Dementia, from a global disease burden perspective, affects between 5% to 11% of the population above 65 years of age and contributes 11.2% of years lived with disability (Deepak, Darshan, Shoban, Abhishek and Goswami, 2019). Currently, an estimate of 46.8 million persons are living with dementia (Alzheimer's Disease International, 2019) and the World Health Organisation's projection shows that the number of people living with dementia worldwide will reach 82 million in 2030 and 150 million in 2050 (WHO, 2019). While a curative treatment for dementia has not been discovered, some forms of dementia can be prevented by managing risk factors such as poor educational attainment, hypertension, and depression (Livingston, et al., 2017). Pharmacological and non-pharmacological treatments can also be used to delay functional and cognitive decline in people living with dementia (Brett, Traynor and Stapley, 2016; Livingston et al., 2017).

Awareness of dementia is very important as it helps in the early detection and management of the disease. However, literature (Alzheimer's disease International, 2012; Cations, Radisic, Crotty and Laver, 2018) suggests that there is still a lack of awareness and understanding of dementia which breeds several misconceptions about the illness in the general public, resulting in gaps in knowledge on dementia. Raising awareness will, therefore, help reduce stigma, improve dementia care and services (World Health Organisation, 2015) in addition to reducing the incidence and delaying the onset of dementia due to early diagnosis (Burke, Hickie, Breakspear and Gotz, 2007).

A systematic study on public understanding of dementia by Cations, Radisic, Crotty, and Laver (2018) shows a poor understanding of dementia with 50% of all the respondents indicating that dementia is an unpreventable and inevitable part of normal ageing which causes some challenges for people living with it and influenced other people's attitude towards them. Therefore, gerontologists and social workers specializing in family and elderly care are strategically positioned through their knowledge and training to help address the physical, psychological, and social effects of poor understanding of dementia on people living with it. This can be done through awareness creation and community education to improve community understanding of dementia and ensure adequate care for people living with it (Parast, 2014).

Socio-cultural and political contexts have been found to influence people's perception of dementia. Historical reviews revealed how people living with dementia in certain periods were condemned as sinners and in some cases were institutionalized because they were deemed unfit to exercise basic human rights (Boller and Forbes cited in Bosco, Schneider, Coleston-Shields, Higgs and Orrell, 2018). Through enculturation, the gradual acquisition of norms and characteristics of a culture, misconceptions about dementia are passively passed from one generation to another (Grusec and Hastings, 2014; Mental Health Foundation, 2015). Poor public understanding of dementia has led to dementia-related stigmatisations in many cultural contexts which transcends regional boundaries (Alzheimer's Disease International, 2012).

It is challenging living with dementia, and the social prejudice associated with the condition which leads to isolation and stigmatisation adds to this challenge (Alzheimer's Australia Report, 2017). It has been reported that 94% of people living with dementia encountered embarrassing situations as a result of stigmatisation while 60% of the carers also reported encountering embarrassing situations brought on by caring for persons with dementia (Alzheimer's Australia Report, 2017). The fear of being stigmatized and socially marginalized has thus caused many people living with the disease to continue to do so in secret (Berwald, Roche, Adelman, Mukadam, and Livingston, 2016; Justiss, et al., 2009). The main aim of this study is to identify the core content of knowledge of how ethnicity influences the social construction of dementia through an appraisal and synthesis of various research evidence on different culture's knowledge and understanding of dementia.

Materials and method

This review adopted the Critical Interpretive Synthesis [CIS] method. The critical interpretive synthesis was developed to synthesize and generate new findings from the flow of a large number of already existing multidisciplinary literature. This method was adopted because, aside from its recognition of the existence of heterogeneity in literature, it posits that differences observed in research findings present opportunity for researchers to move beyond aggregation of findings of studies to interrogate underlying assumptions represented in the literature to generate/develop a more comprehensive understanding of a phenomenon (Depraetere, Vandeviver, Keygnaert and Beken, 2019; Dixon-Woods, et al., 2006). Researchers adopting this method are therefore demanded to be transparent about the research process and to detail their methodological approach to enable other researchers to critically replicate the process and engage it with their synthesis (Kastner, et al., 2016).

Inclusion criteria

Inclusion criteria for this review were:

- (a) Empirical and theoretical literature items conducted in the subject matter and published from 2005 to 2019.
- (b) The literature must focus on cultural, ethnic awareness and perception of dementia.
- (c) The reviewed literature must be written in the English language and should be restricted to published articles and reports.

Search strategy

A general search was conducted using established themes and search items in the following electronic databases: PubMed, Google Scholars, Springer Link, Wiley, Science Direct, JSTOR, Emerald full text, Scopus, EBSCO HOST, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ageline, and Medline. From this search, many journal articles, conferences proceedings, and other related works were found and studied to determine which literature item qualifies to be included. The search terms we used were largely in-depth and they include:

“Awareness of Dementia”; *“Views of caregivers about dementia”*; *“Perception of dementia”*; *“Knowledge of dementia”*; *“Public understanding of dementia”*; *“Beliefs about dementia”* *“Culture and dementia”*.

Purposive sampling was initially used to select the literature items/articles from several databases, then we identified two broad themes relevant to this review: (i) Cultural understanding of dementia and (ii) The impact of knowledge about dementia. The initial search yielded 464 results. The authors screened titles and abstracts to select the ones relevant to the study. Further screening to identify and remove duplicates trimmed the number to 92. The authors then reviewed the abstracts of the selected studies and selected 40 studies. Reviewing the full texts of these studies, the authors finally reduced the number to 32. In all cases, excluded articles did not meet the inclusion criteria (for instance, reporting on items listed in the inclusion criteria). On the whole, therefore, the total number of studies included in the review was 32. We did not conduct a formal quality appraisal of the included literature items in CIS because we observed that even a methodologically flawed study/literature item may have high relevance and may add to the understanding of the phenomenon of interest (Catalano, Holloway & Mpofo, 2018; Dixon-Woods et al., 2006). Similarly, although some studies offered significant detail regarding contextual information, in many studies, this information was absent; making it difficult to explain how structural factors (for instance, policy) might shape perceptions of the studies' participants.

Data analysis

The analysis was done systematically. First, each retained paper was read several times by the researchers to gain an understanding of emerging key concepts. Second, for each of the retained literature item/study, priority categories such as information on study site/area, study design, sample characteristics and findings (both direct quotes from study participants and the researchers' interpretation of the findings) related to public understanding of dementia were extracted onto a spreadsheet generated for data analysis. Although it is always difficult to compare results from different studies that had variations in diagnostic criteria and the extent of case ascertainment, in the third step, we adopted the iterative process of coding the extracted data and checking or comparing with the coding of the sources to ensure that these codes accurately reflected the original study's content. In the fourth step, constant comparison methods were then applied to systematically compare these data (coded extracted data and the coded data in its source) to identify and categorize the data in themes generated in the search strategy.

Results

Cultural and religious understanding of dementia

Culture affects the way people perceive, understand, and give meaning to a phenomenon (Yu, 2014). Different cultures have different understandings about the nature and causes of dementia and this may contribute to how people living with it are treated in the society; older adults with dementia may be stigmatized or even considered to be suffering as a result of how they lived their lives when they were younger; thereby placing the blame on the person living with dementia. Woo (2013) found some level of understanding of dementia among Chinese Americans in a study on knowledge of dementia among Chinese American immigrants. The study revealed that 94.1% of the respondents believe that dementia is a disease affecting the brain; about 60% of the respondents think dementia is part of normal ageing and that

everyone develops loss of memory due to ageing; only 37% believe that dementia can reduce life expectancy after onset, hence they do not readily seek proper diagnostic evaluation and treatment.

Tan, Hong, Luo, Lo and Yap (2012) in their study, revealed that 60% of the Chinese respondents incorrectly identified memory decline as the same with dementia, and 48% believed it is a normal process of ageing. Also 24.3% stated that they would be ashamed of having dementia while 37.7% stated that they would not feel comfortable disclosing it to others if they had dementia; 80.2% chose not to know the diagnosis of dementia with 67.2% avoiding advanced care planning if diagnosed.

Some studies have linked dementia to religion and spirituality. Lawrence et al. (2010) found that some South Asians understood dementia to be 'madness' which resulted from past actions (Karma). This is quite different from the subsequent findings of Brijnath and Manderson (2011) and Mukadam, Cooper, Basit and Livingston (2011) which showed Indian and South Asian migrants in the UK to have understood dementia to be the result of sadness, isolation, anxiety, and loneliness. Qadir, Gulzar, Haqqani and Khalid (2013) revealed that some Pakistani's believe dementia to be a medium through which the older adults' relationship with God deepens and that it enables them to see beyond the physical realm. A recent study by Hossain, Crossland, Stores, Dewey and Hakak (2018) furthers the spirituality angle as it found that some South Asian carers viewed dementia as demons' or God's punishments. The interpretation of Indians living in America is also highly influenced by religion and culture. They refer to dementia with the colloquial term 'Chinnan' which means 'child like', a state resembling second childhood (Shaji, Smitha, Lal, & Prince, in Cipriani & Borin, 2016). The syndrome is considered to be a normal part of aging, not a medical condition and there is a marked tendency to misconstrue symptoms of dementia as deliberate misbehaviour.

Berwald, Roche, Adelman, Mukadam, and Livingston (2016), in a study, which used respondents from Black African and Caribbean ethnic groups in the UK, reported that the majority of the African respondents had no knowledge of dementia and had not known dementia in their home country. The Africans attributed dementia to the normal process of ageing, while some indicated that it is as a result of stress. One of the participants stated: "...there are a lot of factors... it's a stress of life that can cause her to forget the basic keys and that is, maybe she has other stress she's going through..." (P05, Nigerian man, aged 35–44; in UK 9 years; p. 5). Some of the participants argued that it is not for Black Africans: "When you talk about dementia... this is a White, old White peoples' disease, it's not seen as Black people have dementia" (P49, Jamaican man, aged 45–54; in UK 43 years); "If I go back to where I was born, you see, dementia, we don't do dementia in our communities" (P28, Zimbabwean man, aged 45–54; in UK 14 years). In a more recent study by Swindells and Gomersall (2019) in the UK comprising of white British and non-British of mixed heritage and Asian ethnic origins, the authors found improved understanding of dementia among laypersons as many of them identified diet, exercise, active mind, alcohol, and social stimulation as five potentially modifiable risk factors for dementia. However, many of them still believed that dementia is part of ageing and that developing dementia was simply a result of 'bad luck'.

Minority ethnic groups who are migrants in Norway also understood dementia from a religious perspective. In Sagbakken, Spilker and Nielsen's (2018) study, they revealed that minority ethnic groups in Norway believed that dementia is associated with bad karma or a punishment from God. They also viewed symptoms of cognitive impairment as a "normal part of ageing" or as something shameful (not to be exposed) and this led them to delay reporting symptoms for early diagnosis. According to Connell, Roberts, McLaughlin and Akinleye, (2009), religious and spiritual beliefs may differentially impact perceptions of dementia among African Americans with many of them believing that 'God's will' had a hand in determining who developed dementia. This may lead them to believe that medicines will be ineffective in treating a disease that stems from a spiritual cause.

In Denmark, Nielsen and Waldemar (2015) studied knowledge and perception of dementia amongst four ethnic groups which comprised of native Danish, Polish, Turkish and Pakistani immigrants. Evidence from the study showed that Turkish and Pakistani ethnic groups had the lowest basic and epidemiological understanding of dementia while the Pakistanis had the lowest symptomological knowledge about dementia. Additionally, the Pakistani and Turkish groups associated dementia with normal ageing and a form of insanity. The Polish had a good knowledge of the aetiology of dementia while all the four ethnic groups (Danish, Polish, Turkish, and Pakistani) recognised that old age is not a cause of dementia. Amongst the French population, a study by Breining, et al. (2014) showed that they were relatively well informed about dementia, however, the link between ageing and dementia remains unclear and respondents still associated ageing with dementia. This might be because studies showing that memory deterioration with age is different from memory loss associated with dementia have been quite topical (Mevel, Chételat, Eustache and Desgranges, 2011)

In America, the Native Americans had similar belief with the Pakistani in the study by Qadir, Gulzar, Haqqani, and Khalid (2013), they believed that dementia is part of the dying process and therefore hallucinations associated with dementia are considered not pathological, but part of an elder's transition to the next world (Cipriani and Borin, 2016). They believe that hallucination is the communication of older adults with the other side (afterlife) before actually transiting. Exploring African American, Chinese and Latino family caregivers' impressions of the onset and diagnosis of dementia, Mahoney, Cloutterbuck, Neary and Zhan (2005) revealed that there were similarities in reported lack of knowledge about early signs of dementia across the three groups, who attributed their relatives' loss of memory to be a part of normal ageing and therefore not a serious problem to be addressed; a Latino narrated "I thought it was the old age, you know, that's what we call it in my country" (Mahoney, Cloutterbuck, Neary and Zhan, 2005).

Studies in Africa also reveal a poor understanding of dementia which leads to a lot of misconceptions. Amongst the Yoruba ethnic group in Ondo state of Nigeria, Adebisi, Fagbola, Olakehinde and Oguniyi (2016) reported that only 67.4% had ever heard of

dementia. Also some of the participants (28%) in the study stated that people living with dementia should not be taken seriously. Wahab and Ikebudu (2014) revealed that Nigerians have poor understanding and false assumptions about dementia. This makes it difficult for people living with dementia to have an active social life. According to Nwakasi, Heyes, Fulton and Roberts (2019), Nigerian's perception of dementia is influenced by their culture and religion. Nigerians believe that dementia spells the end of life, thus the only thing you can do for people living with dementia is to pray for them. Some Nigerians further interpreted dementia as older people being close to their ancestors and communicating with them. Oguniyi (2018) also showed that in Nigeria, some people believe that dementia is caused by evil spirits and could be cured through prayers and other religious supplications. This according to him, led to vital early treatment time being wasted in the process of taking patients to churches and native healers.

The Xhosas in South Africa also recorded deficient knowledge of dementia with an average occurrence of 53.4% on the knowledge test (Khonje et al., 2015). They (the Xhosas) perceived people living with dementia as being dangerous which has led to many of them having a negative feeling about sharing their homes with family members living with dementia, and they were also ashamed of people finding out that their family member is living with dementia. Mkhonto and Hanssan (2018) also revealed that in Tshwane, South Africa, the people who are mostly of Afrikaner cultural background perceived people living with dementia to be bewitched whenever they act in abnormal and strange ways. The poor knowledge of dementia and the branding of people living with dementia as witches amongst the Afrikaners bring about social isolation for the people living with dementia and their families. One of the participants in the study stated: "If someone, for instance, has baked bread, [a guest may] say 'I am not going to eat it because the granny is a witch'" (Mkhonto and Hanssan, 2018, p. 10). These different understandings of dementia have impacts on the people living with dementia and their families, which will be discussed below.

Impact of low knowledge about dementia

There is evidence that in some cultures, people fear those living with dementia based on their knowledge and perception of their disease. For instance, Mkhonto and Hanssan (2018) reported cases of dementia patients rescued after they had been beaten and kicked out of their homes because their families had no understanding of dementia and believed that people with the syndrome are bewitched. Furthermore, poor knowledge of dementia may also lead to people socially isolate their family members living with dementia. The study further reported that some family members refused to visit or eat with their grandparents living with dementia because they believed them to be witches. It was also reported that people with dementia may suffer from abuse because people may respond with acts of violence towards them if they believe the illness to be caused by witchcraft.

The understanding of dementia from a religious perspective also has adverse effects on the care and treatment of people living with dementia. As revealed by Woo (2013), the Chinese indicated that dementia was a result of what the patients did before; insinuating that those living with dementia are paying the price for their action (Karma). This portrays those living with dementia as people suffering because of their

wrongdoings. This affects the attitudes of their families and caregivers who may feel they should not help those paying the price for their actions. The belief that people living with dementia are receiving punishment from God or being possessed by evil spirits (Sagbakken, Spilker and Nielsen, 2018; Oguniyi, 2018) may lead to a lot of time and money being used in native healing centres and churches that practice exorcism of evil spirits. This will result in time-wasting and the progression of the syndrome to advanced stages before mental health care professionals are consulted.

Some of the empirical studies reviewed showed that in many cultures, dementia is viewed as a normal part of ageing, while others see it as a stereotype which may delay or prevent people from seeking early and proper diagnostic evaluation thus leading to loss of opportunity for timely treatment and increasing the burden on patients and caregivers (Gomersall, 2019; Sagbakken, Spilker and Nielsen, 2018; Swindells and Tan, et al., 2012). A systematic review of literature conducted by Bradford, Kunik, Schulz, Williams and Singh (2009) to ascertain the prevalence of dementia and the contributing factors for missed and delayed diagnoses in primary care revealed that misconstruing dementia as a normal process of ageing can prevent high-quality healthcare associated with early detection. Standridge (cited in Bradford et al. 2009, p.2) argued that the benefits of early diagnosis such as prompt evaluation of reversible causes of memory loss, pharmacological interventions which may slow cognitive decline and most importantly, opportunities for patients and family members to contribute and prepare for future care plan will all be lost due to stereotype of dementia as a normal process of ageing.

People's understanding of dementia or the lack thereof, combined with stigma, can affect their attitude towards those living with the disease. Affirming this in a study that explored perceptions of ageing, dementia, and ageing-associated mental health difficulties amongst British people of Punjabi Indian origin, La Fontaine, Ahuja, Bradbury, Phillips and Oyebode (2007) averred that those living with dementia are accused and blamed for causing their difficulties. The authors continued that some people view the behaviour of those living with dementia as relating to personality, stating that some people just want to depend on others for assistance and they never appreciate the help they receive from others.

Poor knowledge and understanding of dementia can also lead to discrimination, shame, social exclusion, and neglect of the dignity and worth of people living with the condition as people with limited knowledge of dementia tend to use derogatory terms to describe people living with dementia. Studies (Adebiyi et al., 2016; Sagbakken, Spilker and Nielsen, 2018) have highlighted some examples of this: the Chinese used the term 'lao-hu-tu' meaning 'stupid and forgetful at old age', the Latinos used the term 'el loco' meaning craziness. Adebiyi, Fagbola, Olakehinde and Oguniyi, (2016, p. 4) reported among the Yoruba in Ondo State of Nigeria, dementia was interpreted with derogatory terms such as 'ageing disease', 'dull brain' 'disease of insanity' 'Memory loss disease', 'brain disorder', 'disease of forgetfulness'. They also reported that some people living with dementia were scorned. One of the participants in the study stated, with contempt, that they are "madmen walking on the streets". These

terms do not recognize people with dementia as having an illness, rather they are perceived as being stupid, forgetful, and crazy which is disrespectful and derogatory to the dignity of persons living with dementia.

The stigmatisation of people living with dementia also affects their social life. People living with dementia can become embarrassed, self-conscious and suffer reduced social activities because of the negative perceptions and misconceptions about dementia (Wahab and Ikebudu, 2014) Furthermore, the study by Hossain, et al (2018) showed that people hid their relatives with dementia from the community to avoid stigmatisation. They indicated that they were ashamed to talk about it because people will believe that their family or family members did something wrong which resulted in dementia. The fear of social exclusion and shaming, according to the findings of Hossain, et al., (2018) led the families of those living with dementia to abstain from calling Alzheimer's Association helpline because they thought their calls would be tracked and their secret exposed.

Discussion

This paper set out to explore differences in the understanding of dementia across cultures and the impact of low knowledge of dementia. The studies reviewed showed that there is relatively low knowledge of dementia and many cultures view it as part of normal ageing (Berwald, et al., 2016; Breining, et al., 2014; Gomersall, 2019; Sagbakken, Spilker and Nielsen, 2018; Swindells and Tan, et al., 2012). The Chinese American immigrants, African Americans and Anglo-European Americans understand dementia more from the biomedical perspective while South Asians and Chinese misconstrue it to be the result of an individual's actions (wrongdoings). The Yorubas considered dementia to be the same as insanity while the Xhosas and Afrikaners linked it to religion and spirituality, thus labelling people living with the disease witches or people possessed by evil spirits.

There are several identified reasons for the differences in the understanding of dementia. Religion, spirituality, situations, and experiences are some of the factors that influence people's opinions about dementia. Some of the African Americans believe that dementia is a white man's illness because they believe it is more prevalent amongst the whites (Berwald et al., 2016) and several of the Anglo-Europeans have at some point lived with a person with dementia and this improved their understanding of dementia. Religion and spirituality influence some cultural understanding of dementia (Khonje, et al., 2015; Hossain, Crossland, Stores, Dewey and Hakak, 2018; Qadir, Gulzar, Haqqani and Khalid, 2013). This is evidenced by South Asians' belief that dementia is a result of an individual's actions (Karma) and the Afrikaners' belief that it results from bewitchment.

The poor understanding and misconceptions about dementia were found to have severe negative implications on both people living with dementia and their families. Poor awareness and knowledge of dementia lead to social exclusion, discrimination, and reduction in social life. The misconception of dementia also led people to use derogatory terms to describe people living with the syndrome (Adebiyi, et al., 2016; Sagbakken, Spilker and Nielsen, 2018) which further disempowered them and may reduce their dignity and self-worth. Poor understanding of dementia also puts people

living with dementia at risk. The belief that people living with dementia are witches (Mkhonto and Hanssan, 2018), possessed by evil spirits (Oguniyi, 2018) or paying for their crimes (Woo, 2013), may lead people to have a severe negative attitude towards them, as children and community members may accuse them of evil deeds and thus subject them to elder abuse. Believing that dementia is a normal process of ageing (Gomersall, 2019; Sagbakken, Spilker and Nielsen, 2018; Swindells and Tan, et al., 2012) or a spiritual connection with ancestors or gods (Nwakasi, Heyes, Fulton and Roberts, 2019) may also reduce the urgency or importance placed on early diagnosis of the disease which delays the use of both pharmaceutical and non-pharmaceutical treatments to defer the cognitive and physical decline of the patient and other effects of dementia.

The results of this study have implications for policies and social work practice. A common theme amongst the misconceptions of dementia is that it is a part of normal ageing, implying that everyone who gets older will at some point experience dementia. This notion takes away the significance of dementia as a syndrome requiring diagnosis and treatment because a lot of people believe it to be normal and therefore does not require special attention or treatment. If policymakers also perceive dementia to be a normal process of ageing, they would not be concerned with making policies for the treatment and welfare of those living with dementia. Policies are usually consequential responses to social problems and if dementia is not viewed as a social problem then policymakers may be reluctant towards making dementia-friendly policies.

Social work as an empowering profession should strive to improve people's understanding of dementia through education and creating awareness about dementia (Parast, 2014). This is very important because poor public understanding of dementia affects the dignity and worth of people living with dementia because of the disrespect, stigma, and scorn they receive from people with little understanding of dementia. Also, this study will inform social workers who are always culture conscious in the practice of how cultures help construct people's understanding of dementia. Therefore, interventions aimed at increasing awareness should focus on cultural reorientation which is not devoid of understanding and respect of diversity.

This paper, therefore, recommends ways to improve awareness of dementia. Firstly, education can serve as a tool for increasing people's awareness and knowledge of dementia through different avenues like the media, sensitisation programmes, and outreaches. Community education that reinforces recognition of dementia as a disease with social acceptability should also be adopted. The community can be educated about the importance and advantages of getting an early diagnosis, requesting memory assessment when cognitive processing becomes a concern through multi-cultural and multi-lingual material while ensuring the needs of those with sensory limits like vision and hearing loss are recognized in designing the information materials.

Secondly, culturally sensitive education of people on how to recognize and relate to persons with dementia, how to protect people with dementia from abuse and exploitation through faith, business and community leaders, social workers, educators

and health professionals who can help in developing and implementing educational and outreach campaigns should also be considered because the increasing number of people living with dementia calls for increased public awareness and knowledge about the illness in all fields of human endeavour.

Thirdly, advocacy programmes designed to promote positive images of persons with dementia may also help provide people living with dementia, their families, and caregivers with opportunities to share their experiences to improve other people's awareness and understanding of dementia and thereby improve attitudes towards people living with dementia and reduce stigma. Furthermore, advocacy should be tailored in a manner that protects people living with dementia and eradicates dangerous labels attached to them, such as the belief that they are witches, which usually leads to abuse.

Conclusion

The conclusion drawn from a critical interpretive synthesis of studies on public understanding of dementia shows a poor understanding of dementia in different parts of the world. Culture and religion were found to inform people's understanding of dementia to a great extent. The poor understanding of dementia leads to less than appropriate attitude towards people living with dementia. This makes them more vulnerable and at the risk of discrimination, abuse, and stigmatisation while also affecting their ability to receive early diagnosis and treatment.

A major limitation of this study lies in the limited number of cultural groups adopted in this review; thus, future studies can explore more cultural groups. Another limitation is the recognition of the variations in diagnostic criteria of the different reviewed studies. Hence, findings should be interpreted with caution.

References

- Adebiyi, A.O., Fagbola, M.A., Olakehinde, O., & Oguniyi, A. (2016). Enacted and implied stigma for dementia in a community in south-west Nigeria. *Psychogeriatrics, 16*, 268–273.
- Alzheimer's Australia Report (2017). Dementia and the impact of stigma. Retrieved from <https://www.dementia.org.au/files/documents/Dementia-Social-Stigma-Report-2017.pdf>.
- Alzheimer's Disease International (2012). *World Alzheimer report 2012: Overcoming the stigma of dementia*. London: ADI.
- Alzheimer's Disease International (2019). Dementia statistics. Retrieved from <https://www.alz.co.uk/research/statistics>
- Ayalon, L. (2013). Feelings towards older vs. younger adults: Results from the European Social Survey. *Educational Gerontology, 39*(12), 888-901.
- Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British communities' perceptions of memory problems: "We don't do dementia". *PLoS ONE, 11*(4), e0151878. doi:10.1371/journal.pone.0151878.
- Bosco, A., Schneider, J., Coleston-Shields, D.M., Higgs, P., & Orrell, M. (2018). The social construction of dementia: Systematic review and metacognitive model of

- enculturation, *Maturitas*. Retrieved from <https://doi.org/10.1016/j.maturitas.2018.11.009>
- Bradford, A., Kunik, M.E., Schulz, P., Williams, S.P., & Singh, H. (2009). Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer Disease and Associated Disorders*, 23(4), 306–314.
- Breining, A., Lavallart, B., Pin, S., Leon, C., Moulias, S., Arwidson, P., Berr, C. & VERNY, M. (2014). Perception of Alzheimer's disease in the French population. *The Journal of Nutrition, Health & Aging*, 18(4), 393–399. doi:10.1007/s12603-014-0008-4
- Brett, L., Traynor, V., & Stapley, P. (2016). Effects of physical exercise on health and well-being of individuals living with a dementia in nursing homes: a systematic review. *Journal of the American Medical Directors Association*, 17(2), 104–116.
- Brijnath, B., & Manderson, L. (2011). Appropriation and dementia in India. *Culture, Medicine and Psychiatry*, 35, 501–518.
- Burke, D., Hickie, I., Breakspear, M., & Gotz, J. (2007). Possibilities for the prevention and treatment of cognitive impairment and dementia. *British Journal of Psychiatry*, 190, 71–372.
- Catalano, D., Holloway, L., & Mpofu, E. (2018). Mental health interventions for parent carers of children with autistic spectrum disorder: Practice guidelines from a critical interpretive synthesis (CIS) Systematic Review. *International Journal of Environmental Research and Public Health*, 15(2), 341.
- Cations, M., Radisic, G., Crotty, M., & Laver, K.E. (2018). What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys. *PLOS ONE*. 13(4). doi: 10.1371/journal.pone.0196085
- Cipriani, G., & Borin, G. (2014). Understanding dementia in the sociocultural context: A review. *International Journal of Social Psychiatry*, 61(2), 198–204. doi:10.1177/0020764014560357
- Connell, C.M., Roberts, J.S., McLaughlin, S.J., & Akinleye, D. (2009). Racial differences in knowledge and beliefs about Alzheimer's disease. *Alzheimer Disease Associated Disorder*, 23, 110–116.
- Deepak, K. P., Goswami, S. P., Darshan, H. S. & Abhishek, B. P. (2019). *Knowledge and awareness of dementia in general public: a survey study*. Poster presented at the 51 Indian Speech & Hearing Association Conference, Bengaluru.
- Denin, T., & Sandilyan, M.B. (2015). Dementia: definitions and types. *Nursing Standard*, 29(37), 38–42.
- Depraetere, J., Vandeviver, C., Keygnaert, I., & Beken, T. V. (2019). The Critical Interpretive Synthesis: An assessment of reporting practices. Retrieved from <https://biblio.ugent.be/publication/8632968/file/8633835.pdf>
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A.J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6(35). doi:10.1186/1471-2288-6-35

- Grusec, J.E., & Hastings, P.D. (2014). *Handbook of socialization: Theory and research*. Cambridge: Guilford Publications,
- Hinton, L., Franz, C., Yeo, G., & Levkoff, S. (2005) Conceptions of dementia in a multi-ethnic sample of family caregivers. *Journal of the American Geriatrics Society*, 53, 1405–1410.
- Hossain, M., Crossland, J., Stores, R., Dewey, A., & Hakak, Y. (2018). Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence. *Dementia*. doi:10.1177/1471301218800641
- Innes, A. (2009). *Dementia studies: A social science perspective*. London: Sage.
- Justiss, M.D., Boustani, M., Fox, C., Katona, C., Perkins, A. J., Healey, P.J., & Scott, E. (2009). Patients' attitudes of dementia screening across the Atlantic. *International Journal of Geriatric Psychiatry*, 24(6), 632–637. <https://doi.org/10.1002/gps.2173>
- Kastner, M., Antony, J., Soobiah, C., Straus, S.E., & Tricco, A.C. (2016). Conceptual recommendations for selecting the most appropriate knowledge synthesis method to answer research questions related to complex evidence. *Journal of Clinical Epidemiology*, 73, 43–49. doi:10.1016/j.jclinepi.2015
- Khonje, V., Milligan, C., Yako, Y., Mabelane, M., Borochowitz, K., & de Jager, C. (2015). Knowledge, attitudes and beliefs about dementia in an urban Xhosa-speaking community in South Africa. *Advances in Alzheimer's Disease*, 4, 21–36.
- La Fontaine, J., Ahuja, J., Bradbury, N.M., Phillips, S., & Oyebode, J.R. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advanced Nursing*, 60(6), 605–614.
- Lawrence, V., Samsi, K., Banerjee, S., Morgan, C., & Murray, J. (2010). Threat to valued elements of life: The experience of dementia across three ethnic groups. *Gerontologist*, 51, 39–50.
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S.G., Huntley, J., Ames, D., & Cooper, C. (2017). Dementia prevention, intervention, and care. *The Lancet*, 390(10113), 2673–2734.
- Mahoney, D.F., Clutterbuck, J., Neary, S., & Zhan, L. (2005). African American, Chinese, and Latino Family caregivers' impressions of the onset and diagnosis of dementia: Cross-cultural similarities and differences. *The Gerontologist*, 45(6), 783–792.
- Mental Health Foundation (UK) (2015). Dementia, rights, and the social model of disability. Retrieved from: <https://www.mentalhealth.org.uk/sites/default/files/dementia-rights-policy-discussion.pdf>
- Mevel, K., Chételat, G., Eustache, F., & Desgranges, B. (2011). The default mode network in healthy aging and Alzheimer's disease. *International Journal of Alzheimer's Disorder*, 535816.
- Mkhonto, R.N., & Hanssan, R.N. (2018). When people with dementia are perceived as witches. Consequences for patients and nurse education in South Africa. *Journal of Clinical Nursing*, 27, 169–176.
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatric*, 23, 1070–1077.
- Nielsen, T.R., & Waldemar, G. (2015). Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark.

- International Journal of Geriatric Psychiatry*, 31(3), 222–230. doi:10.1002/gps.4314
- Nwakasia, C. C., Hayesa, C., Fultona, J., & Roberts, A. R. (2019). A pilot qualitative study of dementia perceptions of Nigerian migrant caregivers. *International Journal of Africa Nursing Sciences*, 10, 167-174. <https://doi.org/10.1016/j.ijans.2019.03.003>
- Ogunniyi, A. (2018). Challenges faced by Nigerian families dealing with dementia: what can be done? Retrieved from: http://gabiwilliamsalzheimersfoundation.org/assets/img/demo/GWAF%20lecture_2018.pdf
- Parast, S.M. (2014). Social Work and Family care for dementia patients. *International Journal of Current Life Sciences*, 4(8), 4688-4691.
- 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.
- Sagbakken, M., Spilker, R.S., & Nielsen, T. (2018). Dementia and immigrant groups: a qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC Health Serv Res* 18, (910). <https://doi.org/10.1186/s12913-018-3720-7>.
- Swindells, J., & Gomersall, T. (2019). Public perception of dementia risk in the UK: a mental models approach. *Journal of Risk Research*, DOI: 10.1080/13669877.2019.1591486
- Tan, W.J., Hong, S., Luo, N., Lo, T.J., & Yap, P. (2012). The lay public's understanding and perception of dementia in a developed Asian Nation. *Dementia and Geriatric Cognitive Disorders*, 2, 433–444 DOI: 10.1159/000343079
- Wahab, E.O., & Ikebudu, C.J. (2013). Quality of life of patients with early onset dementia in Nigeria. *International Letters of Social and Humanistic Sciences*, 12, 28-42. doi:10.18052/www.scipress.com/ILSHS.12.28
- Woo, B.K. (2013). Knowledge of dementia among Chinese American immigrants. *Asian Journal of Psychiatry*, 6, 351–352.
- World Health Organisation (2012). *Alzheimer's disease international: Dementia: A public health priority*. Geneva: WHO.
- World Health Organization (2015). Dementia, a public health priority. Retrieved from https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_executivesummary.pdf
- World Health Organization (2019). Dementia. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/dementia>
- Yu, Q. (2014). Understanding the impact of culture on interpretation: A relevance-theoretic perspective. *Intercultural Communication Studies*, 23(3), 83-102.