



**University of
Sunderland**

Nwasaki, Candidus, Hayes, Catherine, Roberts, Amy and Fulton, John (2019) A pilot qualitative study of dementia perceptions and experiences of Nigerian migrant caregivers. *International Journal of Africa Nursing Sciences*, 10. pp. 167-174. ISSN 2214-1391

Downloaded from: <http://sure.sunderland.ac.uk/id/eprint/10610/>

Usage guidelines

Please refer to the usage guidelines at <http://sure.sunderland.ac.uk/policies.html> or alternatively contact sure@sunderland.ac.uk.



A pilot qualitative study of dementia perceptions of Nigerian migrant caregivers



Candidus C. Nwakasi^{a,b,c,*}, Catherine Hayes^a, John Fulton^a, Amy R. Roberts^{c,d}

^a Faculty of Applied Sciences, University of Sunderland, Sunderland, UK

^b Department of Sociology & Gerontology, Miami University, Oxford, OH, USA

^c Scripps Gerontology Center, Miami University, Oxford, OH, USA

^d Department of Family Science & Social Work, Miami University, Oxford, OH, USA

ARTICLE INFO

Keywords:

Care
Culture
Dementia
Dementia perceptions
Migrant dementia-caregivers
Nigeria
Psychological burden
Qualitative study
United Kingdom

ABSTRACT

Introduction: Concomitant with the rate at which the United Kingdom's population is aging, the increased number of older adults with dementia, and the decrease in relatives who are available to care for these older adults, there has been an exponential rise in the need for healthcare assistants in the workforce. Since the workforce now comprises of a significant number of migrant healthcare workers, some of whom originate from developing countries like Nigeria, it is important to understand some sociocultural factors that may influence the quality of caregiving provided for older adults with dementia in the United Kingdom.

Objective: To gain an in-depth understanding of dementia perceptions and experiences of Nigerian migrant formal dementia caregivers.

Setting: North East England.

Participants: Six Nigerian migrant healthcare workers employed in long-term care facilities (e.g., nursing homes) that have older adults with dementia.

Methods: Qualitative descriptive method embedded in symbolic interactionism, following a purposive sampling technique and recruitment to the study was used. Semi-structured interviews and thematic analysis were conducted for data collection and analysis respectively.

Results: Cultural specificity, dementia awareness, and empathic witnessing were identified as the three major themes in the findings. The findings suggest that meanings given to dementia symptoms are influenced by sociocultural factors and they may ultimately affect the way people with dementia are cared for.

Discussion: Minimal knowledge about dementia consequently results in minimal appreciation or regard for the seriousness and importance of dementia. When people from communities with different meanings of dementia and little knowledge of the condition become caregivers in developed countries, there may potentially be new psychological burdens that originate from the differing contextual significance of dementia and caregiving for persons with dementia.

1. Introduction

As the world population ages, Alzheimer's disease (AD) and dementia are becoming global health priorities due to their increasing incidence and prevalence (Prince et al., 2013; World Health Organization (WHO), 2011). This global demographic situation is resulting in an increased demand for formal dementia caregivers in countries like the United Kingdom (UK), which has been met through hiring migrants from countries such as Nigeria to work as dementia caregivers. However, research from the perspective of Nigerian migrant caregivers on dementia-related topics is scarce, and little is known

about their perceptions of dementia, which may influence dementia caregiving practices in the new cultural context of the UK. To address this gap, this pilot qualitative study of Nigerian migrant healthcare workers explored some of the culturally grounded perceptions of dementia and their experience as dementia caregivers.

1.1. Dementia as a global issue among diverse cultures

Dementia awareness is a global issue because its symptoms are not well understood, and sometimes, people wrongly view the condition as a normal part of aging (Alzheimer's Disease International, 2012). The

* Corresponding author at: Candidus Chibuzor Nwakasi, 210B Upham Hall, 100 Bishop Circle, Oxford, OH 45056, USA.

E-mail address: nwakascc@MiamiOH.edu (C.C. Nwakasi).

<https://doi.org/10.1016/j.ijans.2019.03.003>

Received 17 October 2018; Received in revised form 7 March 2019; Accepted 25 March 2019

Available online 13 May 2019

2214-1391/ © 2019 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

concept of viewing dementia symptoms as a part of aging has been described in an ethnographic study of family dementia caregivers in India (Brijnath, 2011), and among African and Caribbean participants living in the UK (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016). In rural South Africa, a qualitative study by Gurayah (2015) found that confusion attributed to dementia is understood as a part of the aging process. Another study described that health workers in the Republic of Congo are aware of dementia, but others viewed dementia symptoms as a non-medical condition (Faure-Delage et al., 2012).

In many cultural contexts, stigmatization related to dementia is an issue that transcends regional boundaries (Alzheimer's Disease International, 2012). A study found people in the UK and the US expressed worries over screening because of fear of being socially marginalized because of having dementia (Justiss et al., 2009). Additionally, immigrants living in the UK from African and Caribbean descent reported that they would rather keep dementia a secret and seek help from religious practices and other self-remedies to avoid the stigma (Berwald et al., 2016). The fear of having dementia is reported in some African countries where dementia is believed to be caused by evil spirits (Ogunniyi et al., 2005) or seen as a punishment from God or other mystical powers that can be cured by traditional healers (Khonje et al., 2015). Understandably, Khonje and colleagues (2015) recommend that researchers frame interview questions about dementia with sensitivity to minimize the risk of biases related to social desirability.

To better understand dementia perceptions of Nigerian migrants, it may be important to view dementia awareness in the Nigerian context. Poor dementia awareness in the country may be linked to its low average life expectancy (55 years) from birth (World Health Organization, 2014) as older age increases dementia risk. Its lack of long-term care policies also means poor dementia awareness, and care is usually done by family members even in severe cases (Awosika, Odunbaku, Olley, & Baiyewu, 2003; Ogunniyi et al., 2005). Other risk factors for dementia in Sub Saharan Africa include rural living (Lekoubou, Echouffo-Tcheugui, & Kengne, 2014; Russ et al., 2012), older age (Yusuf, Baiyewu, Sheikh, & Shehu, 2011), and other socio-demographic characteristics such as female gender, illiteracy, and low educational status (Lekoubou et al., 2014). This may differ slightly from the situation in developed regions like the UK where rural living, gender, and illiteracy are not identified as risk factors for dementia; although, similarly, advancing age and low education are identified as risk factors for dementia in the UK (Alzheimer's Association, 2019).

Furthermore, providing specialized care for people with dementia in Nigeria is limited by a shortage of health workers (Kasper & Bajunirwe, 2012), poverty (Berwald et al., 2016), medical co-morbidities, and psycho-geriatric care specialists (Ogunniyi et al., 2005). Since primary care settings are where the majority of older Nigerians receive care (Schubert et al., 2006), primary care providers would rather attend to acute illnesses instead of dementia needs which are often times quite complex (Nilsson, Rasmussen, & Edvardsson, 2013).

1.2. Caregiving and migrant healthcare workers in developed countries

Currently, a large percentage of formal dementia caregivers in developed countries are from developing countries like the Philippines, Poland, India, Zimbabwe, and Nigeria (Hussein & Manthorpe, 2012). This occurs because many people from developing countries migrate to developed countries in search of better opportunities (Aluttis, Bishaw, & Frank, 2014). Immigrants from countries like Nigeria are often called migrant healthcare workers in developed countries (Lopez, 2012), and while educational preparedness varies, Stone (2016) mentioned that some of these workers have educational qualifications that are well beyond the minimum requirements to work as dementia caregivers. Regardless of migrant healthcare workers' educational qualifications, their cultural backgrounds may influence their quality of care. A UK study found that older adults are satisfied with the quality of care

provided by migrant healthcare workers and they attribute it to their culture and religious beliefs towards helping older people (Spencer, Martin, & Bourgeault, 2010).

In the UK, migrant healthcare workers taking care of older adults with dementia may experience caregiver burden. In the caregiving literature, the burden is associated with responses that result from physical, emotional, psychological and even financial stressors often experienced during caregiving (Etters, Goodall, & Harrison, 2008). As the relationship between a caregiver and a care recipient develops over time (Bryon, Casterlé, & Gastmans, 2012), the type of relationship shared by a caregiver and the person with dementia can affect the caregiver's wellbeing (Fauth et al., 2012). Some caregivers may become more compassionate over time and may be emotionally affected by not being able to do more for their patients, due to restrictive organizational policies (Bryon, Casterlé, & Gastmans, 2012). Additionally, having too much empathy may lead to compassion fatigue, causing the caregiver to become either depressed, angry, detached, apathetic, and/or physically exhausted (Boyle, 2011).

Although there are extensive studies about dementia caregiving in developed countries, it is an understudied topic in some developing countries (Mavrodaris, Powell, & Thorogood, 2013; Olayinka & Mbuyi, 2014), and findings from developed countries may not be applicable to the cultural norms of developing nations (Thrush & Hyder, 2014). Moreover, little is known about the dementia perceptions and caregiving experiences of Nigerian migrant dementia caregivers providing dementia care in a new cultural context of the UK. To address this gap, our pilot study used a qualitative approach to understand the dementia perceptions of six Nigerian graduate students who were working as paid dementia caregivers in the UK.

2. Methods

The qualitative descriptive method was embedded in symbolic interactionism a sociological perspective which views meaning as that which is developed from social interaction (Charmaz, 2014). Qualitative descriptive method uses restricted levels of interpretation to provide an honest description of the phenomenon and it allows the use of various philosophical assumptions such as symbolic interactionism (Colorafi & Evans, 2016). This method focuses on capturing the who, what, and where of events, and in the process, gains more knowledge about a poorly understood phenomenon like dementia in a Nigerian context. The cultural similarities shared by the lead researcher and the participants allowed for better probing to gain an in-depth understanding of meanings derived during the data collection process. We argue this method is well suited for studying complex issues like caregiving experiences and dementia perceptions of migrant dementia caregivers.

2.1. Study location and sampling

The study was conducted in Tyne and Wear County, North East England, United Kingdom. The region has residential homes and healthcare facilities for people with dementia and the participants recruited for the study work as dementia caregivers. Purposive sampling was used and included the following criteria to recruit participants: age 18 years and above, Nigerian, formal dementia caregiver in the UK for at least 12 months, under a UK student visa that allows 20 h per week work during school semesters. Invitations were sent via email to Nigerian graduate students in the nursing and public health programs of the University of Sunderland, UK. Physical meetings were conducted with those who responded to the email to explain more about the study and ensure they fit the inclusion criteria. Six participants agreed to participate in the pilot study and they were enrolled after providing informed consent. A total of six participants were in the study (two male and four female Nigerians) and their ages ranged from 24 to 30 years. Among the six participants, five are registered nurses in

Nigeria working as healthcare/nursing assistants due to the limitations placed on foreign students who are not allowed to work as health professionals. The participants are Christians, four are from the Igbo tribe, one is from Ibibio, and one is from Yoruba. The first author is able to interpret and describe meanings in the study because he is from the Igbo tribe and has lived among the people of the other tribes in Southern Nigeria. The participants' names were changed to ensure confidentiality.

2.2. Data collection

The data collection was conducted from April to May in 2014, and the study was completed in August of the same year. Using semi-structured interviews, these Nigerian healthcare assistants were asked questions about AD and dementia, with particular emphasis on: 1) how dementia is perceived in Nigeria and how common they perceive it to be in Nigeria, 2) what did they perceive that caring for a person with dementia entailed, 3) whether their perceptions of caring for a person with dementia changed since working in the UK, and 4) how they perceived their ability to explain the severity of dementia with their current level of knowledge. Five out of the six participants have experience of working in both Nigeria and UK healthcare settings.

The interview questions were not rigid to allow for probing into relevant emerging concepts. Six interviews were conducted and the interview times ranged from 41 min to 58 min. As recommended by Charmaz (2014), memo writing was undertaken concurrently to consolidate the audio-recordings; this process ensured that codes and ideas worthy of further exploration in the emerging categories could be noted down during the interviews. For example, memo writing was used during each interview to note observations ranging from specific words and phrases to physical and emotional expressions of a participant while answering a particular question, as this provided cues on the significance of such questions or area of discussion. The interviews and memo taking were done by the first author, and the interviews were transcribed verbatim.

2.3. Data analysis

Thematic analysis is used to interpret and summarize qualitative data. This captures element of the data that represents the participants' responses that are equally important to the research question (Braun & Clarke, 2006). This iterative process involved line-by-line coding of the transcribed interviews; the codes were assigned themes. The frequently recurring themes were identified and the research team agreed on which ones were relevant to the research question. The interview audio recordings were transcribed, coded, and compared to the themes to see how they fit into the emergent themes. As the key components emerged, coding continued and the main themes were adjusted to include relevant codes. Where necessary, a new theme was developed to group relevant codes that did not fit into the main themes. Exploring dementia perceptions and experiences of the participants underpinned by symbolic interactionism generated themes that encompass what the participants think about dementia. Symbolic interactionism helps us make sense of how views influenced by one's culture are sustained by social interactions (Charmaz, 2014).

Field notes such as memo writing helped the research team stay on track with some emerging concepts that helped to answer the research question (Denzin & Lincoln, 2018). Also, peculiar or significant areas during the data collection were noted and plans were devised on how to probe further. All these were possible using the field notes. For example, the first participant's account contained concepts relating to prayer and indigenous religion and with the field notes, the next participant interviewed was asked their views on prayer and religion as they relate to dementia.

The rigor of the research was maintained by discussing emergent themes, concepts and analytical ideas with team members. The main

Table 1
Study findings indicating dementia perceptions of participants.

Themes	Sub-Themes
Cultural specificity	Praying for someone or something Indigenous religious beliefs Ancestral connections Going with the flow
Dementia awareness	Longevity and life expectancy Dementia is secondary to other-co-morbidities Using aging as an excuse Appreciation of the importance of dementia
Empathic witnessing	They are people's relatives Putting yourself in their shoes Emotional involvement over time

themes developed from the collected data were discussed with the participants to ensure the findings were linked to their responses. This process, known as member checking, is to ensure the study's trustworthiness is upheld. Since the first author undertaking the data collection is from Nigeria, it was possible to ensure that questions were structurally framed in ways that are relatable to the participants. Also, having a similar cultural background with the participants was a valuable tool for the interpretation of meanings conveyed in the interviews. Data saturation was achieved after the fifth interview as it establishes a clear explanation of the relationship between dementia perception and caregiving among the participants.

3. Results

Through participants' descriptions of their cultural views or actions relating to dementia, we are able to see that these migrant healthcare workers are still influenced by dementia meanings from the society they come from and still feel connected to. The resulting themes were grouped into cultural specificity, dementia awareness, and empathic witnessing. This section also includes sub-themes and illustrative quotes (see Table 1 for the themes and subthemes).

3.1. Cultural specificity

Cultural specificity refers to those explanations and meanings, actions and thoughts that are connected to dementia and caregiving pertaining to a particular society and the people that are part of it. According to the study, symptoms of dementia are often times mistaken and confused for other things that are permissible within the socio-cultural premise of that society (Nigeria). Regarding the issue addressed by the study, some of the themes that predominantly were encompassed by "cultural specificity" are: praying for someone, indigenous religious beliefs, ancestral connections, and going with the flow.

3.1.1. Praying for someone

Praying for someone who is suffering or in need may be linked to people's culture. In this sense, it may not matter the type of religion. When someone is perceived as undergoing too much health-related suffering without a foreseeable solution, the likely thing to do according to some of the participants is to pray for the affected person amongst other things. For example, participant B was asked how she would handle a typical dementia case with family members in Nigeria and she said this:

"Although I stand that I will tell the person to prayerfully back it up coupled with the fact that we all believe in God. Prayerfully back it up and provide mechanisms that support."

Another participant (D) also mentioned that back home in Nigeria, being old and having dementia is viewed as approaching 'the end of life' which is why praying for the person with dementia is the only way you can assist in addition to home management.

“The only thing you could do is assist the person with prayers and home management.”

3.1.2. Indigenous religious beliefs

This concept refers to irrational beliefs about aging and dementia symptoms that originate from indigenous, tribal cultures but have been integrated into formal religion in Nigeria. Although Nigeria’s population is made up of about 50% Muslims and 50% Christians, indigenous religious beliefs are still combined with these popular religions (United States Department of State (2015), 2015). Amongst poorly educated people in Nigeria, some of these indigenous beliefs may go without question and are likely shared in families from one generation to the next. Although they are usually devoid of evidence or proof, they are believed by some members of the society as an appropriate description or explanation of a phenomenon. For example, participant D stated that in Nigeria, dementia symptoms may be linked to an older person getting retribution for his/her evil deeds. The quote given was:

“They believe most people that are elderly (with dementia) are not good people, witches or something...it is a myth to some while to some it is real.”

These beliefs sometimes lead to stigmatization and in some cases negatively affects the type of attention that should be given to someone with dementia. This is evident in participant C’s comment that:

“Some people, because they are not educated, will dismiss them as old, aged or possessed.”

3.1.3. Ancestral connections

Participants explained how in African traditional settings like Nigeria, it may sometimes be assumed that a person can have some sort of communication link to their dead relatives as they become very old. This belief that older adults can communicate with the dead is used to explain an episode of hallucination or confusion in an older adult with dementia especially if he/she mentions the name of a dead relative. As participant A said:

“They feel like those elderly people are closer to their ancestors than the younger ones and they can hear things.”

Similarly, participant F had a similar comment to the above quote but wanted it to be clear that it is not what he believes. Hence, he acknowledged that such meanings exist in his society but he does not subscribe to them. He stated thus:

“They could think the gods are at work or maybe he saw spirits of the ancestors of which I don’t buy that because for something to keep happening often and on then there is definitely something wrong. For me that’s what I think.”

3.1.4. Going with the flow

Some of the participants expressed that in a Nigerian society (even in healthcare practice), it is difficult to change the minds of people about meanings they hold about a condition like dementia regardless of your level of knowledge. In such situations, “if you can’t beat them, you join them”, hence the concept “going with the flow”. For example, participant A stated thus:

“If I am back in Nigeria, I would probably go with the flow and say oh yeah you people probably need to go call her pastor because she is now seeing things.”

The above quote shows that regardless of the participant’s adequate level of knowledge and awareness on dementia, cultural beliefs influence the health-related recommendation provided. Even when the participant understands that those views are superstitious, he/she would rather go along with the views of the family affected by dementia

by affirming their irrational ideas. Participant F gave a more succinct response when asked how he could debunk traditional beliefs about dementia. His comments were:

“...well if you can’t beat them you join them. If you keep explaining to them and they don’t seem to buy your explanation, you just do two things. You either walk away or see if you can change their minds or hopefully one day they will come to realize what you were saying was real.”

3.2. Dementia awareness

The attention and importance given to dementia as a health condition with serious implications may depend on dementia awareness in Nigeria. The study found that participants attributed their previous low dementia awareness to three themes, including the longevity and life expectancy in Nigeria is low, dementia is secondary to other pressing co-morbidities in the country, and the use of aging as an excuse for dementia. In addition to the themes mentioned, another concept that is under this theme is “appreciation of the importance of dementia.” The three themes presented below provide an insight into the experiences of these participants in relation to their changing knowledge of dementia.

3.2.1. Longevity and life expectancy

Participants mentioned that the reason they had seen very few people with dementia in Nigeria is because of the very low average life expectancy and longevity in the country. It is estimated that its 65 + age group makes up about 3.12% of its 186 million population (Agency, 2017); and these older adults mostly reside in rural areas. This could be why participants had seen only a handful of people with dementia and the assumption that dementia awareness is low. After Participant A was asked if she has seen people with dementia in Nigeria, she explained:

I would say yes but not to this extent (compared to the UK) because from my background back home, we usually don’t see dementia patients may be because of the life expectancy or because of the onset of the disease or the fact that we don’t get to see people over 80 years or 70 years even.

Another participant (E) who also has experience practicing as a registered nurse in Nigeria had a contrasting view about longevity and dementia but went ahead to acknowledge that there is low average life expectancy and longevity in Nigeria. Her comment was:

“Though people do not live that long in Nigeria, but maybe it is age related but I think it is because people in Nigeria have immunity from it.”

3.2.2. Dementia is secondary to other co-morbidities

According to the participants, dementia is given lesser attention in healthcare settings in Nigeria and other co-morbidities are prioritized. Co-morbidities could be communicable diseases like HIV, polio, and malaria; and non-communicable (chronic) diseases such as heart diseases, and diabetes. More so, it is assumed that a person with dementia would not visit the hospital because of dementia. According to participant A:

“...that’s not why they are in the hospital anyway. They have other co-morbidities that you know, bring them to the hospital but alongside it could be said oh this person has dementia.”

Participant D mentioned how the presence of other diseases limits dementia awareness and response at a macro level. Also, the participant calling dementia a small case is an indication of how she views dementia in comparison to other health burdens. She mentioned that:

In Nigeria, people are trying but not much attention is paid to dementia patients because we have other health-related diseases like HIV to concentrate on which affects a majority of the population. We have polio

that the government is really trying to eradicate so the occurrence of these major cases does not leave room for consideration of smaller cases such as dementia in Nigeria.

3.2.3. Using aging as an excuse

Just as culturally grounded meanings were associated to dementia during the course of data collection and analysis, it was also discovered that being old or saying someone is aged was the explanation given for dementia symptoms in an older adult in Nigeria. Participant C mentioned that:

“When an elderly person is exhibiting forgetfulness, his family will just dismiss it as because he or she is old.”

Another participant (A) spoke of her experience in a healthcare setting in Nigeria where a woman in her late 70s with dementia exhibited poor cognitive symptoms; she was dismissed as being old which is an indication of poor dementia awareness. Her comment:

“...they just hiss then say leave her alone she is old. Exactly, especially when the person is elderly because they just see it as you know as part of being elderly as part of wanting to die.”

3.2.4. Appreciation of the importance of dementia

Based on the cultural background of the participants and their perception of dementia awareness in Nigeria, living and working with people with dementia in the UK resulted in an appreciation of the importance of dementia. Although these participants are educated, they are influenced by the culture of the society they come from and their comments indicated that dementia could be accorded more attention than it is getting in Nigeria. According to participant A:

“I knew a bit about it but it was very new to me and the experience was life-changing because I’ve never seen it as a big deal because in my country it is not a big deal but it is a big deal here.”

Participants also mentioned how experiences from living in the UK and working with people with dementia changed their knowledge and appreciation of dementia. Participant B who had no previous work experience in Nigeria’s healthcare added that:

“I never knew something like dementia existed. The whole thing was just really (pause) what’s the word (longer pause), I was really shocked that something like this existed”.

3.3. Empathic witnessing

The term empathic witnessing refers to participants’ experiences of compassion and deeper understanding that arose as they spent more time caring for persons with dementia. Over time, participants were able to see views about dementia in a society (UK) which differed from theirs. And while caring for people with dementia, they became emotionally involved with people they provide care for. This may be attributed to more appreciation of the importance of dementia by the participants. The sub-themes grouped into empathic witnessing are: they are people’s relative, putting yourself in their shoes, and emotional involvement over time.

3.3.1. They are people’s relatives

Some of the participants indicated that they started caring deeply for persons with dementia they cared for when they imagined them as people with friends and families and how much they mean to their relatives. Such assumptions triggered a feeling of deeper compassion for a person with dementia. Like participants A said:

“It is really a sad thing and it makes you reflect on your own self, your relatives and all that; putting them in the position of the people you care for”

More so, seeing a person with dementia as someone who could be your relative may evoke a certain type of positive proactive response to their needs while caring for them. Just like participant F said:

“You have to still have the empathy as if they are your relatives; seeing them as a relative or possible relatives help to carry out the service they need.”

3.3.2. Putting yourself in their shoes

Similar to imagining people with dementia as people’s relatives or people that could be your relatives, participants imagined that they may also be in such a vulnerable condition when they are older. Assuming the position of people living with dementia puts a somewhat vivid understanding of their plight while caring for them and may raise the urge to do more for them regardless of unfavourable conditions. For example, participant F stated that staff to resident/client ratio is low in some residential homes especially when a significant number of the residents have dementia, and this makes caregiving more difficult. To give his best, he added that:

“I think I have come to understand that it is quite a challenge to care for them and I expect one day I’m going to get older and may have dementia as well. So, I always put myself in their shoes.”

3.3.3. Emotional involvement over time

Most of the older adults the participants in this study cared for started out as strangers but as time went on, they developed some sort of personal relationship with the person for whom they provided care. This was what some of the participants described when talking about their experiences while providing care for people with dementia. More understanding of the challenges of dementia resulted from spending more time with a person with dementia which in turn caused more emotional involvement as stated by participant B:

“It was subsequently that everything started to fall in place and I understood how terrible this disease was and the effects.”

Interestingly, the emotional involvement and compassion which has a positive influence on caring for a person with dementia may equally become a stressor on caregivers. The emotional stress of witnessing someone suffer may become so much that a caregiver might be relieved when the person with dementia dies. Participant B stated thus:

Some of us were frustrated because some situations may come up and you will be like this person should just die and go. There is an adage that says, “o di ndu onwu ka mma” or “you are alive but it is better if you were dead” or “better off dead than alive” situation. So, some situations like that mean trying your best but when the person dies you just shrug and say at least the burden has been lifted.

This traditional “Igbo” (a major tribe in Nigeria) quote is an expression of empathy towards a person who is going through a long-lasting, often terrible, traumatizing experience. A person or observer may become emotionally involved by spending time or observing someone going through severe hardships or struggle like dementia. As a result of this deepening empathy towards their struggle (vicarious feeling of the sufferer’s pain), the person or caregiver may begin to think that death may be the best way to put the person suffering out of his/her misery.

4. Discussion

This pilot study’s objective is to gain an in-depth understanding of dementia perceptions and experiences of Nigerian migrant formal dementia caregivers. The findings show that cultural specificity (praying for someone, indigenous religious beliefs, ancestral connections, and going with the flow), dementia awareness (longevity and life-expectancy, dementia is secondary to other co-morbidities, using aging as

an excuse, appreciation of dementia importance), and empathic witnessing (they are people's relatives, putting yourself in their shoes, emotional involvement over time) help to explain dementia perceptions and experiences of the Nigerian migrant healthcare workers in the study.

Similar to the study, reviewed literature shows that caregivers in developing countries may view dementia as mysterious and part of getting old (Brijnath, 2011; Gurayah, 2015; Berwald et al., 2016). Therefore, it is not surprising that culturally grounded meanings are given to symptoms similar to that of dementia, and the recommendation for religious interventions like prayers or calling for a pastor as the study found. Individuals from participants' communities may see dementia as beyond ordinary or beyond scientific intervention hence resorting to prayers to make the situation better. The problem with dementia care associated with offering only prayers as the main solution to dementia is that it may discredit the use of evidence-based practices to improve dementia care.

In exploring the dementia perceptions of the participants, we found that these meanings attributed to dementia may have implications such as stigmatization and negative effect on help-seeking behavior. The study revealed that sometimes people with dementia are perceived to be facing retribution or some sort of karma for evil deeds committed in the past. Older people perceived as witches are also viewed this way (Khonje et al., 2015; Mkhonto & Hanssen, 2017), so to prevent stigmatization, family members or the affected person may rather keep the dementia status private (Justiss et al., 2009; Berwald et al., 2016). Indigenous religious beliefs surrounding dementia may influence the way dementia care is assessed; they push relatives to cope with living with loved ones with dementia on their own rather than seeking for medical assistance.

Incidence and prevalence of dementia are dependent on several factors that may be genetic, biomedical, environmental and physical. Nigeria's low life expectancy (World Health Organization, 2014) may have added to why little is known about dementia as age is a major risk factor (Yusuf et al., 2011). The study found that regardless of the factors influencing dementia incidence and prevalence, knowledge of dementia by members of a community may be influenced by presence of comorbidities (Ogunniyi et al., 2005) and the perception that symptoms of dementia are a normal part of the aging process (Brijnath, 2011; Gurayah, 2015; Berwald et al., 2016). This is evidenced in one of the participants' statement that Nigeria is burdened by health issues like HIV and polio eradication to bother about what she referred to as "small issues" like dementia. Some of the participants thought dementia awareness is low in Nigeria, and there are other health issues that usually take precedence over dementia (Schubert et al., 2006).

In the study, participants became more empathetic about persons with dementia from imagining them as people's or their relatives. Although a close relationship may lead to positive outcomes for the care recipient and caregiver, it may also cause an adverse psychological effect on the caregiver (Fauth et al., 2012). Empathic witnessing explains how one of the participants who is frustrated by the working conditions in the institution he works, still does his best to provide care for persons with dementia because he expects to eventually become older too and may need help with activities of daily living. Spencer et al., (2010) pointed out that such a level of dedication and quality of dementia care by migrant workers may be because of their religious belief and cultural orientation towards older adults. More so, realizing that dementia is a major issue may create a kind of psychological burden. Sometimes, it is as a result of the emotional investment in the caregiver-care recipient relationship over time or in the question, "Is this what would become of me when I am old with dementia?"

Emotional stress from empathic witnessing was evident in the study which was why one of the participants mentioned how caregivers could get so emotionally stressed with the conditions of some persons with dementia that they wish him/her could die just to be done with the suffering. This kind of stressful feeling leans towards what Boyle (2011)

referred to as caregivers' compassion fatigue which could lead to depression, anger, detachment, apathy, and physical exhaustion. Some of the participants in the study wished they could do more for people with dementia and they tried to in their own way. This increased compassion and willingness to do more for someone who used to be a stranger is in line with Bryon, Casterlé and Gastmans, 2012 study that showed that over time, nurses caring for persons with dementia in hospitals became more compassionate and offered more personalized care to these dementia patients as they became more like family to them (the nurses).

Overall, it can be said that sociocultural factors like prayer, ancestral connections, and indigenous religious practices and beliefs shape the meanings given to dementia in the participants' society. These meanings of dementia consequently determine the kind and level of care given to someone with the condition. Additionally, perceived low longevity and life expectancy of Nigeria by participants, presence of other pressing co-morbidities, and use of aging as a means of explaining dementia symptoms, are indications of low dementia awareness. This, in turn, results in little knowledge about dementia, hence affecting the level of importance given to dementia as a health condition. In terms of practice, when migrant healthcare workers from Nigeria with poor dementia knowledge become formal caregivers, they become more aware of dementia and views can change. But, along with having a deeper understanding of the importance of dementia through first-hand experience, the participants described feeling a new kind of psychological burden.

In the UK, where this study was conducted, the findings indicate that some of the migrants who work as dementia caregivers may have varying meanings about dementia and people with dementia. While their religious beliefs and culture may encourage quality dementia care provision, it is argued that it may not always be the case especially if their knowledge of dementia may be sub-optimal. For example, it is within reason to assume that some migrant dementia caregivers may view some of these older adults as "less than"; and even when these views are not intentionally done to harm the person with dementia, these thoughts may have negative outcomes in regard to the person's quality of life. Training and awareness programs in healthcare settings should be recommended for migrant nursing/healthcare assistants working as caregivers, as this study shows that dementia perception plays a big role in influencing psychological burden which may affect the wellbeing of the caregiver, and may consequently affect the quality of care provided.

4.1. Limitation of the study and future direction

Key limitations of the study include the small sample size as a result of the short time duration of the study. Time constraint also did not allow for a second interview of participants to probe deeper for more involved discussion of this sensitive topic. However, by using highly educated participants, very articulate responses were provided during the interviews that resulted in rich data to answer the research question. It is possible that views on dementia perceptions may be different between these participants and those who are less educated. It is also likely that native or migrant status and formal or informal caregiver role may change dementia perceptions. The findings from this pilot study have informed another qualitative study on dementia perceptions and experiences of female informal dementia caregivers in Nigeria. More research is needed through a larger survey to provide more information about dementia perceptions in Nigeria. Generalizable results from larger studies may help to address the lack of policies regarding aging and dementia caregiving in Africa's largest aging population. Although we cannot claim generalizability from this study, it does contribute to building a greater understanding of the experiences of Nigerian migrants and their views of dementia.

5. Conclusion and recommendations

A qualitative descriptive methodological approach involving symbolic interactionism proved effective in achieving the study objective. The method established which sociocultural factors influenced dementia care and knowledge through illuminating perspectives on dementia and caregiving as perceived by the Nigerian migrant healthcare workers. These are of direct relevance to the provision of dementia caregiving. The study suggests that meanings given to dementia are influenced by sociocultural factors and these meanings may ultimately affect quality of caregiving. Additionally, when migrants from communities with erroneously constructed meanings of dementia and little knowledge of the condition become caregivers in developed countries, there may potentially be new psychological burdens that emanate from the differing contextual significance of dementia care and minimal knowledge of dementia as a serious medical condition.

To provide even greater contextual significance to the study findings, this study indicates the need for more extensive research on perceptions of dementia in the UK which includes the perceptions of both migrant healthcare workers and informal dementia caregivers from alternative global communities. The study also highlights the need for healthcare institution and agency staff in the UK to remain cognizant of the need to provide support for international healthcare workers. Many working as dementia caregivers may have different native cultural perceptions of dementia and the resultant psychological strain of caring for people with the condition. The holistic quality of their lives may also be affected by this process as they provide extensive support and care; and as such, continuing support for migrant dementia caregiving staff is recommended.

6. Contribution of the paper

What is already known about the topic?

- Aging of developed countries is increasing the demand for dementia caregivers and migrants are taking up the roles of formal caregiving.
- Culture influences how people define dementia symptoms
- Dementia caregiving may result in psychological burden on the caregiver.

What this paper adds

- The dementia perceptions and experiences of Nigerian migrant formal dementia caregivers in the United Kingdom.
- Potential psychological burdens that may result from initially not viewing dementia as a serious condition based on poor dementia awareness and meanings of dementia symptoms grounded in a different culture.

7. Ethical consideration and research governance

Ethical Approval was provided by the University of Sunderland Research Ethics Group.

Conflicts of interest

There are no conflicts of interest declared by any of the authors of this research. Also, no funds nor grants were received for this research.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijans.2019.03.003>.

References

- Aluttis, C., Bishaw, T., & Frank, M. (2014). The workforce for health in a globalized context: global shortages and international migration. *Global Health Action*, 7, 1–7. <https://doi.org/10.3402/gha.v7.23611>.
- Alzheimer's Association (2019). Alzheimer's and dementia in the United Kingdom. Retrieved January 8, 2019, from <https://www.alz.org/uk/dementia-alzheimers-uk.asp#factors>.
- Alzheimer's Disease International (2012). World Alzheimer report 2012: overcoming the stigma of dementia. Retrieved July 23, 2017, from <https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>.
- Awosika, G. O., Odunbaku, S. O., Olley, B., & Baiyewu, O. (2003). Supporting caregivers of elderly Nigerians with dementia: The experience of the Ibadan dementia research project. *IPA Bulletin*, 10–11.
- 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. <https://doi.org/10.1371/journal.pone.0151878>.
- Boyle, D. A. (2011). Countering compassion fatigue: A requisite nursing agenda. *Online Journal of Issues in Nursing*, 16(1), 1. <https://doi.org/10.3912/OJIN.Vol16No01Man02>.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <https://doi.org/10.1191/1478088706qp0630a>.
- Brijnath, B. (2011). Appropriation and dementia in India. *Culture, Medicine and Psychiatry*, 35(4), 501–518. <https://doi.org/10.1007/s11013-011-9230-2>.
- Bryon, E., Casterlé, D., & Gastmans, B. C. (2012). Because we see them naked - nurses' experiences in caring for hospitalized patients with dementia: Considering artificial nutrition or hydration (ANH). *Bioethics*, 26(6), 285–295. <https://doi.org/10.1111/j.1467-8519.2010.01875.x>.
- Central Intelligence Agency (2017). The world fact book: Nigeria. Retrieved August 14, 2017, from <https://www.cia.gov/library/publications/the-world-factbook/geos/ni.html>.
- Charmaz, K. (2014). *Constructing grounded theory* (2nd Ed.). London: Sage Pub.
- Colorafi, K. J., & Evans, B. (2016). Qualitative descriptive methods in health science research. *HERD: Health Environments Research and Design Journal*, 9(4), 16–25. <https://doi.org/10.1177/1937586715614171>.
- Denzin, N. K., & Lincoln, Y. S. (2018). *The SAGE handbook of qualitative research* (5th ed.). Thousand Oaks: SAGE.
- Etters, L., Goodall, D., & Harrison, B. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of The American Academy of Nurse Practitioners*, 20(8), 423–428. <https://doi.org/10.1111/j.1467-8519.2010.01875.x>.
- Faure-Delage, A., Mouanga, A. M., M'belesso, P., Tabo, A., Bandzouzi, B., Dubreuil, C.-M., & Nubukpo, P. (2012). Socio-cultural perceptions and representations of dementia in Brazzaville, Republic of Congo: The EDAC Survey. *Dementia and Geriatric Cognitive Disorders [extra]*, 2(1), 84–96. <https://doi.org/10.1159/000335626>.
- Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., ... Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging and Mental Health*, 16(6), 699–711. <https://doi.org/10.1080/13607863.2012.678482>.
- Gurayah, T. (2015). Caregiving for people with dementia in a rural context in South Africa. *South African Family Practice*, 57(3), 194–197. <https://doi.org/10.1080/20786190.2014.976946>.
- Hussein, S., & Manthorpe, J. (2012). The dementia social care workforce in England: Secondary analysis of a national workforce dataset. *Aging and Mental Health*, 16(1), 110–118. <https://doi.org/10.1080/13607863.2011.596808>.
- 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>.
- Kasper, J., & Bajunirwe, F. (2012). Brain drain in sub-Saharan Africa: Contributing factors, potential remedies and the role of academic medical centers. *Archives of Disease in Childhood*. <https://doi.org/10.1136/archdischild-2012-301900>.
- Khonje, V., Milligan, C., Yako, Y., Mabelane, M., Borochowitz, K. E., & de Jager, C. A. (2015). Knowledge, attitudes and beliefs about dementia in an urban xhosa-speaking community in South Africa. *Advances in Alzheimer's Disease*, 4, 21–36. <https://doi.org/10.4236/aad.2015.42004>.
- Lekoubou, A., Echouffo-Tcheugui, J. B., & Kengne, A. P. (2014). Epidemiology of neurodegenerative diseases in sub-Saharan Africa: A systematic review. *BMC Public Health*, 14, 653. <https://doi.org/10.4236/aad.2015.42004>.
- Lopez, M. (2012). Reconstituting the affective labor of Filipinos as care workers in Japan. *Global Networks*, 12(2), 252–268. <https://doi.org/10.1111/j.1471-0374.2012.00350.x>.
- Mavrodaris, A., Powell, J., & Thorogood, M. (2013). Prevalence of dementia and cognitive impairment among older people in sub-Saharan Africa: A systematic review. *Bulletin of World Health Organization*, 91, 773–783. <https://dx.doi.org/10.2471%2FBLT.13.118422>.
- Mkhonto, F., & Hanssen, I. (2017). When people with dementia are perceived as witches. Consequences for patients and nurse education in South Africa. *Journal of Clinical Nursing*. <https://doi.org/10.1111/jocn.13909>.
- Nilsson, A., Rasmussen, B. H., & Edvardsson, D. (2013). Falling behind: A substantive theory of care for older people with cognitive impairment in acute settings. *Journal of Clinical Nursing*, 22, 1682–1691. <https://doi.org/10.1111/jocn.12177>.
- Ugunniyi, A., Hall, K. S., Baiyewu, O., Gureje, O., Unverzagt, F., Gao, S., & Hendrie, H. C. (2005). Caring for individuals with dementia: The Nigerian experience. *West African Journal of Medicine*, 24(3), 259–262.

- Olayinka, O. O., & Mbuyi, N. N. (2014). Epidemiology of dementia among the elderly in Sub-Saharan Africa. Article ID 195750 *International Journal of Alzheimer's Disease*, 1–16. <https://doi.org/10.1155/2014/195750>.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimer's and Dementia*, 9(1), 63–75. <https://doi.org/10.1016/j.jalz.2012.11.007>.
- Russ, C. T., David, G., Gena, B., Hearnshaw, F., Fenton, C., & Starr, J. M. (2012). Geographical variation in dementia: Systematic review with meta-analysis. *International Journal of Epidemiology*, 42, 1012–1032. <https://doi.org/10.1093/ije/dys103>.
- Schubert, C., Boustani, M., Callahan, C., Perkins, A., Carney, C., Fox, C., ... Hendrie, H. (2006). Co-morbidity profile of dementia patients in primary care: Are they sicker? *Journal of the American Geriatrics Society*, 54(1), 104–109. <https://doi.org/10.1111/j.1532-5415.2005.00543.x>.
- Spencer, S., Martin, S., Bourgeault, I., L. & O'Shea, E. (2010). The role of migrant care Workers in ageing societies: report on research findings in the United Kingdom, Ireland, Canada and the United States. Retrieved January 27th, 2017, from https://www.library.nuigalway.ie/bitstream/handle/10379/3217/The_Role_of_Migrant_Care_Workers_in_Ageing_Societies.pdf?sequence=1&isAllowed=y.
- Stone, R. I. (2016). The migrant direct care workforce: An international perspective. *Generations*, 40(1), 99–105.
- Thrush, A., & Hyder, A. (2014). The neglected burden of caregiving in low- and middle-income countries. *Disability and Health Journal [serial online]*, 7, 262–272. <https://doi.org/10.1016/j.dhjo.2014.07.005>.
- United States Department of State (2015). 2014 report on international religious freedom – Nigeria. Retrieved August 18, 2017, from <http://www.refworld.org/docid/56210569e.html>.
- World Health Organization (2014). World Health Statistics 2014. Retrieved September 3, 2017, from <http://www.who.int/mediacentre/news/releases/2014/world-health-statistics-2014/en/>.
- World Health Organization (WHO) (2011). Dementia: a public health priority. Geneva, Switzerland. Retrieved August 17, 2017, from http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1.
- Yusuf, A. J., Baiyewu, O., Sheikh, T. L., & Shehu, A. U. (2011). Prevalence of dementia and dementia subtypes among community-dwelling elderly people in northern Nigeria. *International Psychogeriatrics*, 23(3), 379–386. <https://doi.org/10.1017/S1041610210001158>.