

**PERCEPTIONS AND EXPERIENCES OF DEMENTIA AND ITS CARE IN RURAL
KENYA**

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ETHICS

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ABSTRACT

Objectives: We aimed to explore the perceptions towards dementia and related care across three stakeholder groups in rural Kenya.

Methods: A total of 38 key stakeholders (carers of persons with dementia, health care providers and the general public) participated in focus group discussions. Additional five individual interviews were held with carers. Thematic analysis was used to analyze the data.

Findings: Across the three participant groups, a total of four themes were identified: (i) Negative stereotypes of dementia; (ii) Limited knowledge about dementia; (iii) Diagnostic pathway and; (iv) Neglect and abuse.

Conclusions: We found a general lack of knowledge of dementia amongst family carers, healthcare professionals and the general public. The combination of poor awareness and ill-equipped healthcare systems leads to stigma manifested in the form of patchy diagnostic pathways, neglect and abuse. Local governments could take advantage of the existing family- and community-based systems to improve understanding of dementia nationally.

Key words: Stigma, dementia, knowledge, stereotypes, Kenya

INTRODUCTION

There is a huge treatment gap for dementia in Low- and Middle-Income Countries (LMICs) where majority of the population with the condition reside. The Kenyan health system continues to face critical challenges in addressing dementia and long-term care such as early dementia detection, diagnosis and treatment. National priority agendas for health are often centered towards health needs for children or adults of reproductive age with little focus on older persons and priority conditions such as dementia (Alzheimer's Disease International, 2017). This contributes to low numbers of trained specialists and limited health care facilities which are difficult to reach for many people (Mendenhall et al., 2016). Moreover, high levels of stigma and discrimination towards psychiatrists and patients with dementia and other types of mental and neurological conditions (Gaebel et al., 2015; Ndeti, Ngumi, Zipporah, Mutiso, Musyimi, & Kamau, 2013) may also contribute to uncoordinated pathways to dementia care. These low levels of resources and negative perceptions can have profound effects on the person with dementia and their carers leading to depression, social isolation, loneliness, diminished quality of care and reduced health-care seeking (Farina, Suemoto, Burton, Oliveira, & Frost, 2020; Tan, Yeo, Koh, Wong, & Lee, 2020).”

The future situation is likely to be worsened by the change in demographic profile with an increase in the number of older persons and persons living with dementia (M. Prince et al., 2015). Despite the lack of formal long-term care for dementia in Kenya and in other LMICs (Ferri & Jacob, 2017), increasing evidence indicates a strong need to promote early diagnosis and improve dementia care access in such settings (Maestre, 2012; Magklara, Stephan, & Robinson, 2019; M. J. Prince, Acosta, Castro-Costa, Jackson, & Shaji, 2009). Specifically, studies conducted in Sub-Saharan Africa have outlined a need for dementia carer training

(Gurayah, 2015), strengthening family-based care and collaboration between formal and informal dementia care (N. Agyeman et al., 2019; Mushi et al., 2014), health care worker and community awareness on dementia (Mkhonto & Hanssen, 2018) due to increasing rates of dementia reported in some countries (N. A. A. Agyeman, 2019; Uwakwe et al., 2009). However, there is lack of scientific evidence in Kenya on perceptions towards dementia-related care which could assist policy makers to develop and adapt anti-stigma interventions, and integrate the needs of people living with dementia and their carers, community members and health care providers into health policy, planning and practice including resource allocation to reduce the impact of dementia.

The World Health Organization (WHO) has published international guidelines on management of dementia in LMICs, (World Health Organization, 2016) but in Kenya, individuals and families receive a diagnosis late after dementia onset or never receive a diagnosis, leaving a gap that needs to be addressed.

Stigma and discrimination associated with dementia is likely to have a profound impact on care quality and access and can manifest itself in a number of ways. In the Kenyan context, there is a general absence of evidence surrounding dementia, including prevalence (Farina, Ibnidris, et al., 2020). Notably, there is no research on the perceptions of dementia in Kenya, which is consistent with the dementia stigma literature in Africa as a continent (Nguyen & Li, 2020). Evidence surrounding stigma and perceptions can be potentially inferred from other Sub-Saharan African countries. For example in Nigeria, participants would use stigmatizing terminology to refer to dementia (e.g. “madman”) and associate the condition with shame and embarrassment (Adebiyi, Fagbola, Olakehinde, & Ogunniyi, 2016). However, it is important not to assume that this would be the same or similar in Kenya, as such countries are culturally very different.

In order to develop accessible dementia care services that are contextually and culturally relevant, it is crucial to understand the drivers, facilitators, and manifestations of stigma. As such, this study aimed to explore perceptions and experiences of dementia and related care in rural Kenya. This novel study will explore the views of various stakeholders (health care providers, members of the general public and carers of persons with dementia) in order to lay the foundation for adapting relevant interventions to improve dementia care and quality of life of persons with dementia and their families locally and nationally.

METHODS

Design

We conducted a qualitative study with three stakeholder groups through in-depth interviews, to provide fundamental data on the views and contextual experiences of multiple stakeholders on dementia related care in rural Kenya. Qualitative approaches also provide a deeper understanding and descriptions that are expansive while giving a clear picture of what it means to be in a particular situation (Arnout, Alshehri, Assiri, & Al-Qadimi, 2020). We recognise that the way in which people conceptualise a disease affects how stigma manifests and ultimately how society treats those with the disease. We conceptualise dementia as an incurable, progressive neurodegenerative condition, that is not a normal part of aging, but is one in which people can live well with. Through the Health Stigma and Discrimination Framework (Stangl et al., 2019), we sought to explore real-life experiences to understand the drivers, facilitators, stigma ‘markings’ and manifestations of stigma on dementia care, which can vary across contexts and have profound effects on health and the society. In adopting this framework, we attempted to move away from the notion of the ‘stigmatized’ and the ‘stigmatizer’ by developing themes across samples, in recognition of the broader social and cultural forces that structure stigma.

Study setting

All participants were recruited from Makueni County, Kenya, which is located in a rural setting and where the poverty line and literacy levels are below the national average (Diwakar & Shepherd, 2018; Government of Makueni County, 2018). The county was selected primarily because of high levels of mental health related stigma (Mutiso et al., 2017; Ndetei et al., 2016), limited access to dementia care due to its rurality, but also because of existing networks with gatekeepers in the region, thus maximizing the success of recruitment. The county has one referral hospital with a mental health clinic manned by psychiatric nurses who generally provide basic counselling and medications prescribed by non-specialist doctors, six sub-county hospitals, 21 health centers, 137 dispensaries and 25 private hospitals (Government of Makueni County, 2018). Similar to many rural counties in Kenya, there is also an enormous reliance on traditional and faith healers to address mental and neurological health problems in the county (C. W. Musyimi, Mutiso, Loeffen, Krumeich, & Ndetei, 2018; C. W. Musyimi, Mutiso, Musau, Matoke, & Ndetei, 2017). These informal community health providers are not formally trained in dementia care; but, they possess important skills such as building rapport and often have long-term relationships with their patients, an attribute valued by community members and which promotes mental wellbeing throughout the caring process. Generally, the dementia care system is also not well established in Kenya and care is predominantly provided by family carers in all counties (C. Musyimi, Mutunga, & Ndetei, 2020; Suárez-gonzález et al., 2020).

Participants

General public: Local village chief were asked to identify adults from different gender groups who had informal (e.g. hawkers, drivers, village elders, traditional healers) or formal employment (e.g. teachers, village administrators, salaried office workers) and who were willing

to participate in the research. We sought a balanced representation of each group to share diverse opinions.

Healthcare workers: Recruitment was facilitated by the medical superintendent of the County referral hospital who approached the heads of the different cadres to invite healthcare workers to participate in the Focus Group Discussions (FGDs). This composition was to ensure equal representation of each cadre with a role in dementia care (e.g. medical officers, mental health professionals and social workers).

Carers of persons with dementia: Participants were identified by psychiatric nurses through the county referral mental health clinic. Carers who accompanied people living with dementia were referred to the research team for consent explanation and inclusion in the discussions.

Procedure

Between June and September 2019, a series of FGDs were conducted to explore key stakeholders' perspectives and experiences of dementia and related care in rural Kenya. We interviewed 43 participants through five independent FGDs (6-8 participants per group) with healthcare workers (2 FGDs), members of the general public (2 FGDs) and carers of people with dementia (1 FGD). FGDs offer the opportunity for interaction between research participants while encouraging them to overtly discuss any inconsistencies at the individual level or across participants to allow the researcher to gather knowledge and ideas on any shared experiences (Kitzinger, 1994). Our participant groups were ultimately defined by their previous experience (or inexperience) of dementia. The FGDs were homogenous in terms of educational level (i.e. formal and informal members of the general public were interviewed separately) and profession (e.g. unpaid carers, health care workers) to prevent dominant voices from taking the centre stage

during discussions as they are often assumed to be experts (Smithson, 2000). Furthermore, Kenya is a hierarchical (and collectivist) society, and therefore a heterogeneous group may have further suppressed certain voices. However, we offered carers the possibility of being interviewed in a group setting or individually, and five carers preferred the latter.

Interview process: FGDs were tape recorded and lasted between 60-90 minutes and were conducted in a quiet and private room to avoid interruptions. Individual interviews lasted 40-45 minutes. Decisional capacity to participate was assessed through discussions on the nature of study and written informed consent was obtained by all participants in the research prior to commencing the research. Interview questions were created for each target group specifically by the research team and all interviews were conducted by a Kenyan, female, and multilingual qualitative researcher (CM) with more than seven years' experience in community mental health research. Across all key stakeholder groups, there was a core set of questions related to dementia knowledge, attitudes, and local idioms related to dementia. In order to ensure that everyone had a common interpretation of dementia term, we provided a brief description of the symptoms associated with the condition and the local common term [mostly, *thing'ai*] was unanimously agreed by participants and used throughout the interviews. Additional context surrounding the etiology, diagnosis, care or treatment were not provided by researchers. However, we included a set of questions that were tailored to experiences of the key stakeholder group (see supplementary material). For example:

- **Healthcare workers:** *“how do people get a diagnosis of dementia? How do other health professionals, patients and families talk about dementia in your clinic?”*

- **General public:** *“What kinds of people get dementia in your community? What happens when people get dementia?”*
- **Carers of persons with dementia:** *“How did you get a diagnosis of dementia? How did you feel when you found out?”*

The interviewer did not have any pre-existing relationship with the research participants prior to the study. Discussions started with introductions, completion of a demographic questionnaire, followed by an ice breaker session. Healthcare workers and formal sector FGDs were conducted in English while informal sector and carer’s FGDs/interviews were conducted using the local language “*kamba*”.

Data analysis

Demographic information was reported descriptively. A multi-linguist researcher (external to the research team but with experience in social sciences) transcribed verbatim and translated the transcripts from the native language to English while maintaining the original meaning. Using inductive thematic analysis with generation of data-driven codes and themes rather than pre-conceived themes to allow the researchers to make patterns of shared experiences was performed in six phases (Braun & Clarke, 2012; Silverman, 2013). Due to the novelty of research in this setting, we did not want to assume that the findings would align with those reported in geographically close, albeit culturally distinct settings. In phase one, transcripts were initially read and re-read by a researcher (CM) to become familiar with the data while taking note of any preliminary interpretations. In phase two, CM performed line by line coding of the transcripts. Phase three involved generating themes from the codes formed across all participant groups. In phase four, an iterative process of reviewing the themes with reference to phase three coding and

the dataset was performed as a quality check. Phase five involved refining themes by NF, and later through team discussions. In phase six, the main themes and subthemes across key stakeholders were reported narratively and supported by anonymized quotes. Themes unique to individual groups were also considered and reported and were highlighted within the narrative.

Ethics and rigor

Ethical approval was sought from the Maseno University Ethical Review Committee (MUERC) in Kenya and Research Ethics Committee of the London School of Economics and Political Science in UK. We ensured that all translations maintained the original meaning as much as possible. Words that did not have a direct translation were maintained in the original idiom, with an explanation provided. Codes and themes were discussed with an independent researcher (NF), living outside Kenya, allowing for the researchers to reflect on the codes and potential influence introduced by CM's experiences of dementia in Kenya.

All themes were discussed amongst a broader group of researchers of the Strengthening Responses to dementia in Developing Countries (STRiDE) project team, running similar qualitative research within their countries. However, there was no attempt to obtain consensus across countries with regards to themes or how they are worded.

FINDINGS

The overall mean age for carers of persons with dementia, members of the general public and healthcare workers was 50.8 (SD= 16.10), 41.7 (SD = 13.84) and 34.8 (SD =7.00), respectively. Healthcare workers had the highest educational level (tertiary education) while, in the other categories, at least one person had less than primary school education. Half of the carers were

either working on voluntary basis, retired or unemployed. The majority (94%) members of the general public were employed (*Table 1*).

A total of four themes relating stakeholders' perspectives and experiences of dementia and related care in rural Kenya were identified: (i) Negative stereotypes of dementia; (ii) Limited knowledge on dementia; (iii) Diagnostic pathway and; (iv) Neglect and abuse.

(i) Negative stereotypes about dementia

Stereotypes were common across all participants and were formed of negative connotations, misperceptions based on culture and tradition (i.e. it is a normal part of aging).

Negative labels attached to dementia: In the rural communities, the term dementia (*'Thing'ai'*) as described by all participant groups originated from the English term "thinking high" and was assumed to affect those of a higher social class and those living in large cities. Many participants believed it was associated with social isolation after retirement and relocating to rural areas, which led to increased feelings of loneliness.

When it comes to, 'thinking high' it means that person thought too much until the Kamba [local language] man, when he heard the English man say that one is 'thinking high' he name it, 'thing'ai' which means, 'dementia' (R2 - Carer).

If you were a manager or regional manager of a big organization in Africa and you were always 'thinking high', you become antisocial and do not interact with people in the village, and it reaches a time when you finally retire. At this point, you go back to the village and realize you

are not able to interact at the high level. This makes you feel lonely and thereafter you develop dementia” (R5 - General Public).

Although this term was commonly used in communities, participants recognised that it was derogatory. Several participants (spanning across stakeholders) considered this term disrespectful towards persons with mild dementia.

People feel degraded since that is a very bad name used on them. Personally, I shared that dementia sounds like a disease that attacks dogs, that’s for sure” (R9 - General Public).

Most of the people take it [dementia] negatively because of the weight of the word. It is like you are telling them that they cannot think well again, or that they cannot do things as usual” (R3- Healthcare Workers).

Other terms or explanations of dementia that might be considered stigmatizing included madness, losing network [similar to how a phone loses connection and is not able to function normally], or not being able to comprehend things. Across stakeholders, participants believed that those who had dementia behaved like people who were abusing drugs such as cannabis. There was the universal use of the term ‘thing’ ai’ even in healthcare settings because they felt it was the only term that communities could understand to refer to dementia. In all the groups, participants reported that alternative friendly and acceptable terms could be used to reduce social isolation and increase access to services in healthcare settings. However, throughout the discussions, participants were unable to identify a non-stigmatizing single term for dementia as the condition presents with a myriad of symptoms which cannot be summed up to one term.

Traditions and cultural beliefs: Across all participants, it was believed that dementia was associated with being cursed, bewitched, or as a way of acquiring wealth rapidly through consulting ancestral spirits [referred to as ‘*majinis*’]. In addition, community cultural beliefs led participants to view dementia as having failed to perform a certain task, whilst home relocation after the death of a spouse was considered as “neglect of a dead husband”. These associations resulted in access to traditional and faith healers (rather than trained healthcare professionals) or self-isolation to avoid stigmatizing attitudes in the communities.

It [dementia] is addressed as a curse or witchcraft according to the Kamba traditions” (R3-General Public).

I normally reside within the local community and once the community members see a person with dementia, they associate it with acquiring ‘majinis’ [demons] in order to become rich, just like the way my fellow clinician said. They state that “Majinis” are disturbing him/her because they want blood sacrifice. Secondly, you find the local community associating someone with dementia with witchcraft. Either the person bewitched someone and it backfired, or they are being bewitched. Thirdly, people say that either the person stole from a home belonging to a traditional healer or a home with a local security done by a traditional healer but also associated with the person being bewitched” (R2-Healthcare Worker).

People would tell my mother [with dementia] who had relocated from where the husband was buried to settle elsewhere, that because she left her dead husband where they initially lived, that could be the contributing factor to her condition” (Carer 6).

However, it was evident from members of the general public that belief in God (often taught by faith healers) could contribute to improved response to dementia treatment as it influences how a person copes with stressors.

Lack of faith in God is a contributing factor to poor prognosis of dementia. When one sees things from an angle of impossibilities, burdening their brains with impossibilities may cause them to be more sick. (R4- General Public).

Normal ageing and ageism: In all groups, participants felt that community and healthcare providers did not consider dementia a priority since it was seen as a normal part of ageing. This resulted in negative attitudes towards older persons with dementia who were stereotyped as ‘old babies’.

I have always thought that dementia is due to old age. At a certain age, elderly people are ‘turning to old babies’ and forgetting all they were doing, just like small babies” (Carer 2)

All of us in the community take dementia symptoms for normal situations that happen in life. It could easily pass for one is old” (R6-General public)

Such views were also shared among healthcare professionals, despite feeling that this view was problematic.

This is not easy for us; possibly because we don’t take it as a big issue. For someone who is experiencing memory loss, we just assume it is because he/she is aging and take it as a normal process of aging. Therefore, it is not taken as a medical condition that requires management. It

is something we have learnt to stay with. The main reason for visiting the hospital would not be because of dementia but a different problem” (R2-Healthcare worker).

(ii) Limited knowledge about dementia care and treatment

Participants across all groups highlighted evidence of limited knowledge about dementia, care and treatment. This theme was often heavily linked with the negative stereotypes theme, presented above. Unlike the previous theme, there was often a clear distinction between knowledge of dementia care based on participant group, which is unsurprising because of each group’s relevant experience with dementia.

Carers’ knowledge: Dementia was reported as a “European rather than an African disease”.

Carers stated that persons with dementia were rude particularly when they were not able to follow instructions to perform a certain task. Lack of awareness was also revealed among carers who relied on previous experiences of other family and community members with similar symptoms to suspect dementia rather than taking the person to the hospital for proper diagnosis.

I noticed unfamiliar behaviour with him [person with dementia] which at first I mistook for rudeness. Some minor issues would arise; like for instance one day we went to purchase a plot somewhere and considering that he was the family Secretary, he was supposed to take down notes but he did not know what to write yet he has been taking notes during all our meetings. When he asked me what to write, I was shocked and asked what he normally writes. He became very emotional and tearful and I took the book and documented the minutes. When we left the meeting, I asked him why he refused to document our meeting activities, yet he knew that was his

role. He told me that he was not aware that he had refused to write. I then considered that as ignorance and left him alone” (Carer 4).

I had heard some other sick people in the community that demonstrated similar symptoms as my mother [person with dementia]. Indeed, there was a particular man, just the age of my mother who behaved in a similar way and so it was from that experience that I heard of a disease called dementia. Therefore, when I saw my mother display such symptoms, I concluded that she too was suffering from dementia” (Carer 1)

General public knowledge: Some members of the general public stated that they were not aware that dementia was an illness and mentioned that they had not considered being “forgetful”) as the reason to seek care.

For instance where I come from, I have never heard anyone with dementia being taken to hospital for treatment neither have I known dementia to be a disease that can be treated. All we know is; dementia is a disease that sets in with old age and one begins to be forgetful and is referred to as a very forgetful person. Personally [mockingly] have never heard or seen anyone go to the hospital because they are too forgetful” (R9-General public)

Healthcare professional knowledge: In healthcare settings, healthcare workers did not often detect dementia as a primary condition and referred suspected cases of dementia to specialist clinics because of lack of knowledge or expertise on how to detect dementia or due to fear of being victimized by individuals of a higher social status.

Firstly, some healthcare workers are afraid of medical legal issues especially when the relatives are well off. Secondly, most of the time we immediately refer suspected cases of dementia to the

mental health clinic because the queue is shorter or if the relatives are anxious to get a quick solution” (R7- Healthcare Workers)

Most of our health workers are not really well equipped on diagnosing and the management of dementia” (R1- Healthcare Workers).

(iii) Diagnostic pathway

Carers and members of the general public reported having had negative experiences in relation to the process of diagnosis disclosure due to poor clinician communication and limited consultation time, resulting in insufficient provision of information on the condition.

Poor interaction between clinicians and patients: This was repeatedly reported as a barrier to accessing the appropriate information and care from healthcare providers. In some cases, persons with dementia and their carers were given medication, but were not informed about the diagnosis or the nature of the condition.

Personally I have never been told that he suffers from dementia but I take him to clinic regularly. No one explained to me what was written in the diagnosis results (R4- Carer).

Whilst not directly associated with experiences of a dementia, the general public also described instances where the communication of a diagnosis was not always forthcoming.

Just to back up participant 9 and participant 3 as they shared something very important. Even where one believed to be having dementia visits the hospital, they lack confidence to ask the doctor the details about the disease. Many times when we visit the hospital, the doctor has no time to explain to the patient details of the diagnosis (R6- General Public).

Some healthcare workers stated that family members were more focused on getting information for physical conditions compared to dementia, equated dementia with normal ageing and therefore did not see this as a problem that needed to be addressed. On the contrary, other health care workers within the same group affirmed carers' statements revealing that dementia was not seen as a priority in health care settings with further discussions culminating in mixed and wide ranging interpretations of dementia by family members such as being a mental health problem, part of normal ageing and cultural attributions such as witchcraft, hence leading to different perceptions about care.

Patients with dementia are often seen last, unless they have other issues. Generally it's not seen as an emergency or a priority and it will not be given so much attention (R5- Healthcare Workers).

Actually dementia is not taken very serious in our society. Relatives are interested to know more about what can be done for conditions like a heart disease or a lesser terminal cancer than dementia. They are not even interested in knowing if there is anything else that can be done for dementia care except to simply take care. They take it like an aging process and there is no problem (R2- Healthcare Workers).

Dementia is neither described in a positive nor negative way. Some families take it as just aging, but others might interpret it as a mental health problem, or due to cultures and beliefs such as curse or witchcraft just like some of us have said. The families' understanding therefore makes treatment to vary (R4- Healthcare Workers).

Limited time to disclose dementia diagnosis: Carers empathised with healthcare workers as they are likely to be overwhelmed due to long queues and may not have had sufficient time to systematically disclose dementia diagnosis or the purpose of the prescription to them. However, this left them dissatisfied with the quality of care and resorted to discontinuation of using the services.

I once enquired because I wanted to know what the prescription I got was made to treat. I got curious because laboratory results didn't show any sickness I had. Nevertheless, from the laboratory I was sent to a different room to collect my prescription. I asked what the medicines were made for and what I suffered from. From my observation, I simply thought the doctor was tired and overwhelmed by the number of patients that were waiting to be seen. He rebuked me and I left the room. He didn't seem to have time to explain to me the purpose of the medicine. I was hurt, did not buy the medicines either and simply went home" (R6- Carer).

In healthcare settings, dementia has no cure: From the perspective of the healthcare workers, they stated that they did not actively treat dementia and would tell patients that dementia comes with age and has no cure. This demonstrates a clear manifestation of stigma within the diagnostic pathway.

Dementia is usually a condition that is not actively investigated or treated, depending on the social status of the patient. Some of the persons with dementia will probably be told there is a drug that will help improve their symptoms, but for the extreme ages after 80 or 90, one talks to their relatives and tells them this comes with age and there is nothing much we can do about it" (R5-Healthcare worker).

However, some health care workers stated that they treated dementia by providing symptom reduction medications, recognizing that dementia could contribute to reduced quality of life and required treatment.

“We treat all patients with dementia symptomatically, for example: anti-psychotics to reduce the symptoms and neural-proteins just to boost the brain“ (R3 – Health care worker).

(iv) Neglect and abuse

Stigma associated with dementia in terms of the responsibilities associated with the care giving role exposed persons with dementia to neglect due to inconsistent or lack of carers. A limited number of paid carers for a person with dementia was attributed to perceived carer burden or financial constraints from the family. This contributed to maltreatment (discriminatory actions e.g. being locked up, thus exposing persons with dementia to risk of injuries and self-harm; and abusive behaviour e.g. physical and sexual abuse) thus impairing their quality of life in terms of service access, emotional and social challenges.

Recently my mother came home with swellings and fresh scars and I heard she was beaten somewhere in a market. I imagined she may have taken other peoples' things and was severely beaten leading to the injuries (Carer 1)

From the perspective of healthcare professionals, there appeared to be a prevalent view that carers (i.e. family and friends) are at least partially responsible for this neglect and abuse.

First of all, we all know that in our society anything which cannot be explained is taken as witchcraft. In this case, before any patient comes to our facility, they have already been locked

up and neglected. Either by family members, friends or by people from social networks (R7- Healthcare worker).

These patients with dementia can suffer a lot especially on the social life and when the carers are not taking much care to them. For instance, we have had cases of those patients who have been left alone by carers they are even defiled by people (R4- Healthcare worker).

Healthcare professionals recognised that carers would use the hospital as a means to get rid of the person with dementia. In some instances, persons with dementia would be brought to the hospital by relatives or community members who would knowingly assume hospitals as “residential care homes” resulting in neglect due to long hospital stays.

In the medical wards, that's where people usually come and dump their relatives who have been neglected at home with dementia. They stay in the hospital for a long time and discharging them becomes a challenge because probably the children have grown up and have gone to the city” (R6-Healthcare Workers).

This neglect could be partially explained by family members’ reluctance to adopt the carer role, not least because carers felt that the community did not hold the caring role in high regards. It was recalled that community members would avoid such roles, leaving the person with dementia with limited alternatives to accessing care.

The community is very ignorant about dementia issues. When some people are approached for hire to care and support people living with dementia they clearly state that they are not the type to care and support people with dementia (R6-Carer)

DISCUSSION

This study was set out to explore how key stakeholders in rural Kenya viewed dementia and related care. The findings indicate that there are interconnected themes that appear to be derived from low awareness of dementia. This appeared to lead to the use of potentially discriminatory terminology, but in some instances could feed into a breakdown in diagnostic pathways, abuse and/or neglect.

Dementia in communities was represented using demeaning terms such as thinking high, losing network [losing one's mind] and also equating it to being due to cannabis addiction. These idioms reflect how local understanding of dementia is rooted in the local culture, and were used even after ensuring that the participants had a common understanding of dementia. Similar to use of local idioms for other mental disorders (Kaiser et al., 2015), our study reveals a greater risk of harm in identifying a single term for specific mental health conditions, based on the symptom presentation or perceived attributions. For example, the term “thinking high”, locally referred to as ‘*Thing'ai*’, was used because persons with dementia who did not previously engage in family or community meetings in rural areas were considered to be too proud and community members equated this to the proverb “*what goes up must come down*”. We argue that a model of ethno psychology incorporating emic/etic approaches could be used in such cases to identify culturally appropriate terms (Mendenhall et al., 2019) that avoid stigmatizing labels with the aim to promote increased treatment seeking behaviour. The Japanese government, for example, has changed the term used for dementia to avoid negative connotations associated with the word (‘*Chiho*’) (Takeda, Tanaka, & Chiba, 2010).

Dementia was also commonly attributed to witchcraft, a prevalent ascription in Africa (Brooke & Ojo, 2020; C. Musyimi, Mutunga, & Ndetei, 2019). This has potentially contributed to more persons with dementia accessing the services of traditional health practitioners (e.g. witch doctors, herbalists, faith healers) without necessarily seeking care from healthcare professionals, which might be seen as a key barrier to receive a diagnosis. This appears to be in line with literature in the region describing the use of traditional and faith healers to address mental health problems (C. W. Musyimi et al., 2018). However, this could be seen as an opportunity to harness the expertise of traditional health practitioners since they are acceptable and reside within communities. Traditional health practitioners could promote social inclusion of persons with dementia and their carers if actively engaged. Collaborative mental health initiatives in Kenya and other settings (Hindley et al., 2017; C. W. Musyimi, Mutiso, Nandoya, & Ndetei, 2016; C. W. Musyimi, Mutiso, Ndetei, Henderson, & Bunders, 2017; Nortje, Oladeji, Gureje, & Seedat, 2016) have revealed evidence of how such care providers can be used to detect dementia, reduce stigma and provide psychosocial interventions for various mental illnesses.

Similar to other LMICs (Ferri & Jacob, 2017; Johnston, Preston, Strivens, Qaloewai, & Larkins, 2020; M. J. Prince et al., 2009), dementia was not considered an illness across groups but rather as part of the normal ageing process or due to witchcraft, or both, and was not considered as being a priority in healthcare settings due to lack of knowledge or prior training on dementia symptom presentation. Past experiences and knowledge of dementia in the family/community was one of the only reasons for people to suspect dementia in other community members displaying similar symptoms. This is a common practice in most LMICs and dementia is not perceived as requiring medical intervention, resulting in stigma and failure or delayed access to care (Ferri & Jacob, 2017). Raising awareness, experience and protest against any inequalities

are all seen as key pathways to address dementia stigma (Mukadam & Livingston, 2012), though future research needs to better understand which culturally appropriate strategies are effective to these different groups within Kenya.

In healthcare settings, dementia was not systematically disclosed to patients due to the assumption that it is a normal part of ageing. Within the Health Stigma and Discrimination Framework (Stangl et al., 2019) this selective disclosure would represent a manifestation of stigma, which in turn influences the outcome (i.e. not receiving a diagnosis). In other circumstances, when dementia was disclosed to patients, carers felt that clinicians were not transparent or forthcoming enough about the diagnosis, its cause and prognosis. It might be that community associations of dementia to witchcraft and negative cultural attributions could have resulted in limited disclosure with the ultimate goal of controlling the negative effects of stigma, which is often cited as possible reasons why healthcare professionals do not often provide an early/timely diagnosis (Dhedhi, Swinglehurst, & Russell, 2014; McLaughlin & Laird, 2020). A recent review (Poyser & Tickle, 2019) exploring dementia diagnosis disclosure experiences revealed a need for developing evidence-based guidelines to improve interaction between healthcare providers, persons with dementia and their carers, and to provide a safe environment for healthcare workers to manage tensions, while giving hope and supporting families during follow-up visits. This could ultimately reduce denial, neglect and mental health conditions related to poor diagnosis disclosure (Samsi & Manthorpe, 2014).

We found that unavailability of paid carers or stigma related to the carer role mainly contributed to neglect and consequently physical and emotional abuse. Although caring for a person with dementia requires specific skills and can be mentally and physically draining (Prince M, Prina

M, 2013), both paid and unpaid carers in Kenya lack the appropriate formal training to deal with responsive behaviours exhibited by the care recipients, making the role challenging. As a result, most carers are not willing to adopt this role as the payment is not attractive for the responsibilities involved or in most cases requires a higher fee which is unaffordable to most families in LMICs. Families are therefore left with no alternative other than using the existing family system of care, also due to filial piety existent in most African settings (Oppong, 2006). This option is a possibility for persons with dementia to be exposed to neglect as families experiencing financial challenges are likely to focus more on looking for employment opportunities for the family sustenance than providing direct care to one person. Issues of blame-game between family and healthcare systems also arise where both parties accuse each other of neglect. Previous evidence has indicated the importance of establishing collaboration between carers and health professionals with the aim of taking carers' cultural values and integrating them in health care service provision to promote social inclusion (Gray, Robinson, Seddon, & Roberts, 2010).

Despite Kenya's weak health system on dementia care (C. Musyimi et al., 2020; Suárez-gonzález et al., 2020), there exists a unique opportunity to utilize community-based programs to train carers and community health providers. The fact that traditional and faith healers are commonly being accessed for those with dementia, similar to those with mental disorders in the region (C. W. Musyimi et al., 2018; C. W. Musyimi, Mutiso, Musau, et al., 2017), they could also be an important target for such training. Ensuring increased awareness across multiple levels of the community, would ultimately reduce stigma associated with care, but also enable the person with dementia to be supported adequately and subsequently promoting the quality of life of persons with dementia and their families.

STRENGTHS AND LIMITATIONS

Our study included a small group of individuals residing in one rural region within Kenya, and therefore the findings may not reflect the opinions of those living in wealthier urban regions.

The carers reported to be providing care for people at the later stages of dementia. Anecdotally, this appears to reflect the tendency of individuals to seek diagnosis and support later in the course of the illness. As such, carer's perceptions and experiences will reflect those that have experienced the progressive nature of the condition, and perhaps some element of adaptation and coping. These views may differ for those carers in the earlier stages of the condition. It also means that they have probably accessed healthcare services in the past, which may not be the case for other carers. Carer data included were collected with both FGDs and individual interviews (n= 5). The choice to use both methods allowed us to obtain a more comprehensive picture without excluding people who might be comfortable to share their views and experiences in a group setting.

Another limitation of the study was the necessity to engage with gatekeepers (e.g. village chief, psychiatric nurses) to identify participants. Whilst the gatekeepers provided a pragmatic solution to recruitment and trustworthiness of the research, it did mean that their involvement could have biased who ultimately took part in the research. Notably, the gatekeeper could have identified those who might have opinions and experiences that align with their own. We attempted to mitigate this risk by having prior discussions with these gatekeepers to clearly explain the purpose of the study, risks and benefits of participation, and inclusion criteria.

CONCLUSION

In this study, we identified limited knowledge of dementia amongst family carers, healthcare professionals and the general public in rural Kenya. The combination of poor awareness and ill-equipped healthcare systems appears to lead to patchy diagnostic pathways and environments that allow for stigma to manifest into neglect and abuse. However, we argue that there is an opportunity for local governments to utilize family- and community-based systems including traditional healers, faith healers and community health workers to improve understanding of dementia by developing culturally acceptable terms relating to dementia locally, adapt dementia care guidelines, and provide formal trainings to carers. The ultimate goal is to promote culturally appropriate services and respond to stigma and treatment gaps with the aim to promote social inclusion and improve the quality of life of persons with dementia and their carers in Kenya. Our findings also revealed a need for development of evidence-based guidelines to address poor clinician-patient interaction during diagnosis disclosure and treatment process to reduce tensions, promote responsive services, and improve dementia care in healthcare settings.

In addition, with the increase in work from home and social distancing regulations to prevent COVID-19 pandemic spread, persons with dementia and their carers have faced further challenges not least because they are not able to access the existing care support (Comas-Herrera et al., 2020; C. Musyimi et al., 2020). This article highlights a gap that needs to be taken into consideration while developing or adapting interventions to combat stigma related to dementia also during the pandemic.

DECLARATION OF CONFLICTING INTERESTS

The authors declare that there is no conflict of interest.

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TABLES

Table 1: Socio-demographic characteristics, split by participant group.

		Healthcare workers (n=14)	General public (n=17)	Carers (n=12)
Age; Mean (Range)		34.8 (28-50)	41.7 (18-65)	50.8 (25-86)
Sex; n (%)	Male	7(50%)	11(64.7%)	4(33.3%)
	Female	7(50%)	6(35.3%)	8(66.7%)
Highest level of educational level; n (%)	Less than primary school	0 (0%)	1(5.9%)	2(16.7%)
	Primary school	0 (0%)	1(5.9%)	2(16.7%)
	Secondary school	0 (0%)	6(35.3%)	4(33.3%)
	Tertiary Education	14(100%)	9(52.9%)	4(33.3%)
Employment status; n (%)	Employed	14(100%)	10(58.8%)	5(41.7%)
	Unemployed	0 (0%)	0 (0%)	4(33.3%)
	Retired	0 (0%)	0 (0%)	1(8.3%)
	Part time paid employment	0 (0%)	6(35.3%)	1(8.3%)
	Unpaid carer/ Voluntary work	0 (0%)	1(5.9%)	1(8.3%)

SUPPLEMENTARY MATERIALS

Health care workers Guide

1. Initial warm up questions

- a) How did you find out about this research?
- b) What made you want to participate in this study?

2. Experiences of working with people with dementia in your clinical practice

- a) Do you work with people with dementia in your clinic?
- b) How do people get a diagnosis of dementia in your clinic?
 - i. What happens when someone gets a diagnosis of dementia?
 - ii. What kinds of things do people report are wrong with them when they come to the clinic?
 - iii. Who usually brings them to the clinic? Do they come by themselves?
- c) What kinds of treatments do people receive for dementia? How is the problem presented?
 - i. How effective are they?
 - ii. How easy are they to access?
- d) Where can practitioners get information on dementia and treatment?
- e) Do health professionals have good knowledge about diagnosis and treatment in your clinic?
- f) Did you receive any training on dementia? Was this training sufficient? Is anything more needed?
- g) What kinds of information do you tell a patient who receives a diagnosis of dementia?
- h) Their family?
- i) Is it similar or different then when you deal with other health problems? How?

3. Knowledge, attitudes and behaviour towards people with dementia and their carers

- a) Do we have good evidence for what causes dementia?
- b) What kinds of things cause dementia among the patients you see?
- c) From your experience, what kinds of things are most helpful for people with dementia?
 - i. Medical treatment
 - ii. Actions by family/community
- d) What kinds of things that are harmful for people with dementia?

4. Local idioms, language

- a) How do other health professionals talk about dementia in your clinic?

- b) How do patients and families talk about dementia in your clinic?
- 5. Current practices to promote social inclusion and thoughts and preferences about how we can reduce stigma and create more inclusive communities**
- a) We are interested in what kinds of things can be done in your healthcare setting to support people with dementia. Are there things that people in your healthcare setting do already which are helpful?
 - b) How would you increase awareness about dementia in your healthcare setting?
 - c) What kinds of people or organisations would be important to work with?
 - d) Are there other things that can be done to help support people with dementia?

General Public Guide

1. Initial warm up questions

- a) How did you find out about this research?
- b) What made you want to participate in this study?

2. Knowledge, attitudes and behaviour towards people with dementia and their carers

- a) What kinds of people get dementia in your community?
 - i. Can anyone get dementia? Why / why not?
 - ii. Do you know anyone with dementia?
- b) What happens when people get dementia?
 - i. How might things change for someone with dementia? For their family?
 - ii. What kinds of things might help people with dementia?
 - iii. Are there things that are harmful for people with dementia?
 - iv. Are there certain tasks or roles that people with dementia might not be able to do? Why?
 - v. What causes dementia?
 - vi. Do you think there are any treatments for dementia? How do they work/help people? Are these easy to access? Would most people know how to access them?

3. Local idioms, language

- a) How do people talk about dementia in your community?
- b) What kinds of words do people use?

4. Current practices to promote social inclusion and thoughts and preferences about how we can reduce stigma and create more inclusive communities

- a. We are interested in what kinds of things can be done in your community to support people with dementia. Are there things that people in your community do already which are helpful?
- b. How would you increase awareness about dementia in your community?
- c. What kinds of people or organisations would be important to work with?
- d. Are there other things that can be done to help support people with dementia?

Carers of people living with dementia guide

1. Initial warm up questions

- a) How did you find out about this research?
- b) What made you want to participate in this study?

2. Experiences of having dementia

- a) How did the person you are taking care of get a diagnosis of dementia/ What happens when one gets a diagnosis of dementia?
- b) How did you feel when you found out?
- c) Did you ever feel like you wanted to hide the diagnosis of the person you are taking care of? Why? Did you tell anyone about your diagnosis? Who?
- d) Thinking about before the person you are taking care of received a diagnosis, could you tell me about whether your life changed when the person you are taking care of received a diagnosis? How
 - i. At home or work?
 - ii. What about in your relationships with friends and family?
 - iii. In the community?
 - iv. Did it help you in any way?
 - v. Hurt you in any way?

3. Local idioms, language

- a) How do people talk about dementia in your community?
- b) What kinds of words do people use?

4. Knowledge, attitudes and behaviour towards people with dementia and their carers

- a) Have you learned more about dementia since the diagnosis of the person you have been taking care of?
 - i. What kinds of things have you learned? How?
 - ii. Do you feel you know what causes dementia?
 - iii. Do you think there are good treatments for dementia? How do they work/help people? Are these easy to access?
 - iv. What kinds of things might help people with dementia?
 - v. Are there things that are harmful for people with dementia?

5. Current practices to promote social inclusion and thoughts and preferences about how we can reduce stigma and create more inclusive communities

- a) We are interested in what kinds of things could be done in your community to support people with dementia. Are there things that people in your community do already which are helpful?
- b) How would you increase awareness about dementia in your community?
- c) What kinds of people or organisations would be important to work with?
- d) Are there other things that can be done to help support people with dementia?