

“They are perceived to be witches, and some are killed”: Community perceptions of elderly people living with dementia in Kilifi, Kenya

Journal of Alzheimer's Disease
2025, Vol. 103(2) 593–604
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DOI: 10.1177/1387287241303931
journals.sagepub.com/home/alz



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Abstract

Background: The risk of dementia, including the most common form, Alzheimer's disease, is forecasted to increase in low- and middle-income countries due to longer lifespans and the rising prevalence of non-communicable diseases. However, little research has been conducted on the knowledge and perceptions about dementia in rural communities in Kenya.

Objective: To explore the community's knowledge, attitudes, and perceptions about dementia in Kilifi County, a resource constrained rural coastal area in Kenya.

Methods: We conducted an ethnographic study comprising five focused group discussions (n = 35, each with 7–8 people) and 25 key informant interviews with various stakeholders from Kilifi County. The interviews and discussions were recorded, transcribed verbatim and thematically analyzed.

Results: There was a general lack of knowledge about dementia by community members. People suspected to have dementia were labeled using stigmatizing and derogatory words such as “neurologically deficient”, “crazy”, or “wendawazimu” [mad person]. Dementia was also associated with normal aging. Others associated neurodegenerative behaviors associated with dementia to witchcraft or curses. This led to individuals suspected to have dementia being isolated from the community, neglected, dispossessed assets, killed or denied medical care.

Conclusions: Dementia is not well understood in Kilifi County, Kenya. People with dementia are stigmatized, neglected and socially excluded from community. Our results could be leveraged by the Kenyan government, the healthcare system, and communities to develop policies and strategies for protecting elderly people with dementia and improving their care, especially in rural areas.

Keywords

Alzheimer's disease, attitudes, dementia, Kenya, knowledge, perceptions

Received: 19 September 2024; accepted: 18 October 2024

Introduction

It is forecasted that by the year 2050, close to 250 million people globally will be living with dementia—a general term encompassing multiple neurocognitive disorders that impair healthy brain function.¹ Sixty-eight percent of the affected will be living in sub-Saharan Africa (SSA)² with East Africa (EA) and North Africa reporting the highest increase in the number of new cases due to population growth and aging.^{3,4} Ranked the fifth leading cause of

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death and disability worldwide, Alzheimer's disease (AD) is the most common form of dementia.^{4,5} However, despite recognizing the threat AD and related dementias (AD/ADRD) pose to physical, social, mental, and cognitive health, it is neglected in SSA. According to Alzheimer's Disease International's report on Dementia in Sub-Saharan Africa: Challenges and Opportunities,⁶ for example, few studies have focused on AD/ADRD research in SSA to the extent that we do not know actual incidences or prevalence of AD/ADRD in the region, including Kenya. Data on the epidemiology of dementia almost exclusively emanates from the Global North societies.

Early identification of the risk factors for AD/ADRD is key in timely management of the disease. Recent studies across the globe have postulated that its risk factors include a genetic predisposition, low level of education, chronic complications of hypertension and diabetes, smoking, physical inactivity, air pollution, female sex, hearing loss, traumatic brain injuries, and persistent depressive disorders.^{7–11} Risk factors are not clearly defined in SSA but are presumed to be similar with other countries, given the risk profiles described in other African cohorts¹² as cited in,^{13,14} yet this remains under-researched.

The symptoms of AD/ADRD include diminished memory, decision-making, learning capacity, and communication.¹⁵ When the general understanding of these symptoms is poor, community members develop misconceptions and myths that complicate the challenges of living with dementia and hamper efforts to educate communities about high-risk modifiable behaviors and available treatment options for dementia.⁶ In Tanzania, for example, people still believe that dementia emanates from supernatural forces such as curses and witchcraft.¹⁶ In Nigeria, members of the community consider the development of dementia a natural process of aging that does not require medical care, psychological care, or social emotional support.¹⁷ Such myths, misconceptions, and cultural beliefs have led to discrimination, stigmatization, and abandonment of people with dementia, their family members and caregivers¹⁸; increased the fear of and violence towards people with dementia,¹⁹ hindered access to dementia care services,²⁰ and hampered the development of programs for addressing the needs of people with dementia in some resource-poor settings—worsening neuro-cognitive functioning and lowering their quality of life.¹⁹ This trend is worrying because the prevalence of dementia is on the rise in Africa.^{4,13}

There is dearth of knowledge about dementia prevalence and attitudes in Kenya. Because Kenya has not ratified a dementia care policy or an advocacy program that can safeguard the health, rights, and safety of people living with dementia, they still compete for basic healthcare services with other population groups.²¹ When symptoms of diminished memory, thinking, orientation, learning capacity, language, and judgment are thought to emanate from witchcraft

or curses, people with dementia are unlikely to receive adequate care.²² Finally, because family members such as spouses, children or grandchildren are the primary caregivers for people with dementia in African settings,^{23,24} this often leads to caregiving burden characterized by emotional distress and burnout in part due to a lack of knowledge on how to care for their patients, physical strain, poor emotional support, and a struggle to deal with the feelings of guilt for not being able to care for their loved ones or grief when their loved ones die.^{25–27}

We conducted an ethnographic study to explore the community's knowledge, attitudes, and perceptions about dementia in Kilifi County, a resource constrained coastal area in Kenya. Findings from this study will pave the way for developing comprehensive and evidence-based dementia policies, and interventions that aid in the creation of dementia-friendly communities.

Methods

Ethical considerations

The study was approved by the Aga Khan University, Nairobi Institutional Scientific and Ethics Review Committee (2022/ISERC-141 V3), National Commission for Science, Technology & Innovation (NACOSTI/P/23/24196) and the Department of Health Services, county government of Kilifi. Written informed consent was obtained from participants. Participants' confidentiality was maintained by de-identifying participant information and storing all the information under lock and key in a cupboard located at Aga Khan University's (AKU) Brain and Mind Institute (BMI).

Study design and setting

We conducted an ethnographic study between March and May 2023 within the Kaloleni-Rabai Health and Demographic Surveillance System. Kaloleni and Rabai sub-counties are among the poorest regions of Kenya²⁸ and were selected as the AKU's field sites in consultation with the Kilifi County government due to unavailability of population-level health data and suspected poor population health indicators relative to other parts of Kilifi County.²⁹ The sub-counties lie between latitudes 3° 38' and 39° 59' South and longitudes 39° 21' and 39° 39' East (Figure 1). They cover an area of approximately 909 square kilometers and have a population of around 352,175 people in about 47,000 households. In 2010, Kilifi County had approximately 40,168 people who were 70 years and above of age.³⁰ Currently, the population is projected to have increased to 48,379 based on a growth rate of 3.05% per annum. This represents 3.62% of the projected population of around 1,336,590. About 70% of

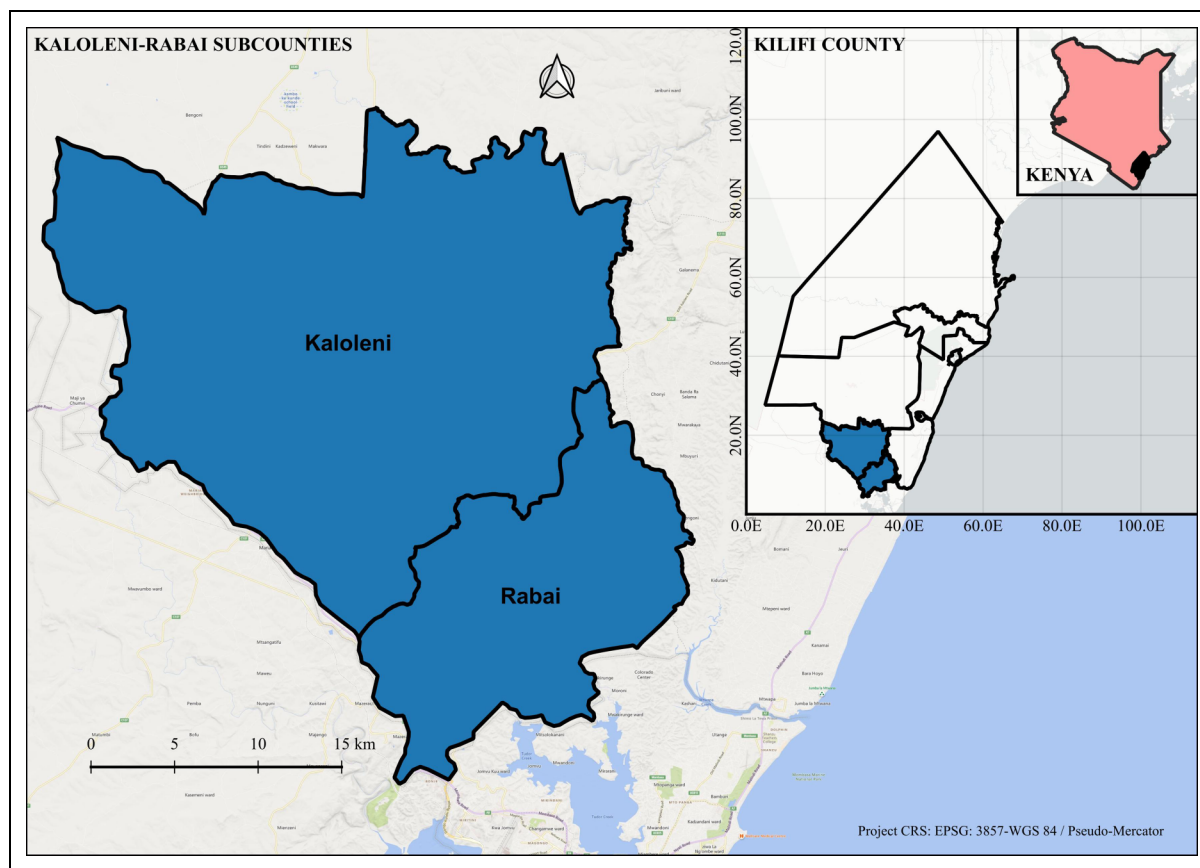


Figure 1. A study map showing the location of Kilifi County, Kenya, and the sub locations (Kaloleni and Rabai) where the study team collected data.

residents of Kaloleni and Rabai live below the poverty line. Eighty one percent rely on subsistence agriculture, crafts, casual labor, and petty trading for their livelihoods.²⁸

to get others who may be interested in the stakeholder engagement.

Sample size and sampling strategy

We used purposive sampling to recruit 60 participants from communities within the Kaloleni and Rabai sub-counties. Participants aged 18 years and above who were residents of Kaloleni-Rabai, and consented to take part in the study were included. Participants included researchers or academicians working in Kaloleni and Rabai sub-counties, healthcare workers and managers, community leaders and key decision makers, community gatekeepers such as chiefs, and assistant chiefs, traditional and faith healers, and community health volunteers (CHVs).

To get a representative sample, we liaised with the AKU lead of the KRHDSS cohort to help us identify key participants we could interview. The AKU staff had established a good community rapport. This was helpful in gaining access to the target populations. In addition, we used snowballing techniques, especially for policy makers, where we interviewed a stakeholder and asked for referrals

Data collection

We conducted five focus group discussions (FGDs) (n = 35 with each FGD comprising of 7 people) with CHVs, health care workers, and chiefs and assistant chiefs from both rural and urban areas. We also conducted key informant interviews (KII) (n = 25) with various stakeholders including healthcare workers and policy makers (n = 10), community leaders and gatekeepers such as chiefs, traditional healers and faith healers (n = 10) and researchers working in Kilifi County (n = 5). Interviews and FGDs with healthcare workers and CHVs were conducted within healthcare facilities in Kaloleni and Rabai sub-counties while interviews with health managers and other key policymakers were conducted in their respective offices in Kilifi County. The FGDs were audio-recorded. One research assistant (RA) took exhaustive notes as a backup for the audio files. Discussions, which took 60–120 min, were conducted in Kiswahili, a commonly spoken language in these settings. Most interviews with researchers were conducted online

using the Zoom platform. KII took an average of 60 min to complete and were conducted in either English or Kiswahili. Lastly, we conducted ethnographic observations to understand aspects such as access to hospitals, schools, and water points; income generating activities; and the existing cultural artefacts among others. These observations were flexible but were largely guided by the study objectives.

Data analysis

Data collection and analysis were conducted concurrently. The audio files were transcribed verbatim. Transcripts from field notes were also incorporated into the analysis. Qualitative data was thematically analyzed using a constant comparison method³¹ between different categories (e.g., community groups and health care providers, managers and other cadres). The data was analyzed according to the six steps of constant comparison (data familiarization through reading and re-reading transcripts and listening to the audio recordings, initial code generation, searching for themes, reviewing, and naming themes, comparing themes across different categories and reporting). Initial code generation was done by ENB and LK. They read and re-read the transcripts from audio files and field notes and categorized data into themes. Thereafter, the two, and one more researcher, LW, individually reviewed the themes and immersed themselves into the data to verify whether the themes were related with different sources of data. The group then met and discussed the data including individual data categorization, which was later discussed by the whole research team. Any identified discrepancies were resolved at this point. Together, we developed, tested, and refined a data codebook that was used for coding the data and analysis. We then identified key themes and sub-themes related to study objectives, and any other emerging themes. Following coding, we resumed our group meetings to complete data analysis and interpretation of themes until no new themes were identified. We finally came up with four main themes and several sub-themes. The main themes included: (a) Knowledge and understanding of dementia (b) Perceived causes of dementia, (c) Community perceptions of Dementia, and (d) Threats exposed to elderly people suspected of having dementia.

Results

Theme 1: knowledge and understanding of dementia

We explored people's understanding of and existence of dementia in the community. Interviews with policy makers, healthcare providers and some researchers working in Kilifi demonstrated a good understanding of dementia. In addition, participants associated dementia

with "aging" and "memory deterioration". Participants, especially those working in healthcare facilities, revealed that they had seen a few cases of dementia in the hospitals:

"So, dementia amongst the old people, yes. Those cases are there". (Healthcare provider, Rabai sub-county)

"Yeah, it's a, it's, it's a common problem also for the elderly, yeah, I think I've come across several cases." (Researcher, Kilifi)

However, there was a significant lack of understanding of dementia amongst other non-health community stakeholders such as gatekeepers, religious and traditional leaders. During FGDs, participants mentioned that the terms "Dementia" or "Alzheimer's" were complex, and they had never heard of such conditions as exemplified here: *"I have not heard about dementia before. Is it a disease?"* (FGD with Faith healers, Kaloleni). Most of them asked us to elaborate or describe further what we meant by the term "dementia". Once we described and elaborated on dementia, participants—especially those who took part in FGDs—were able to relate to dementia terming it as *"Ugonjwa wa kusahau sahai"* meaning a "disease of forgetfulness". Other participants used words such as "elderly populations losing memory," or "people whose memory is deteriorating."

"The elderly people that I have seen in our community, some have lost their memory, wanasahau sahai [they are forgetful]." (FGD with Traditional healers, Kaloleni)

"Many elderly people are often oppressed in our community because, they might be strong physically, but their memory has deteriorated." (KII with a healthcare provider, Rabai)

In comparison with dementia, the knowledge of and understanding of other neurological conditions such as epilepsy and mental illnesses such as stress, depression, and substance use was good, even among non-health community members, and were said to be common in their communities. This was largely due to a history of epilepsy research and stigma-reduction campaigns that sensitized the community to epilepsy diagnosis and care. In addition, mental illnesses such as substance use disorders and depression were said to be common and that several organizations were working to address these illnesses within the Kaloleni-Rabai communities.

"Epilepsy is more known than dementia. It's been talked about in many places. You hear about it on the radio for instance but also, you wouldn't go to a village and miss out on a person who has ever had fits. I would say it's a bit more common than dementia." (KII with a researcher working in Kilifi County)

“The brain issues which we have here is epilepsy. That’s the common mental issue which we experience at the facility.” (KII with healthcare provider, Rabai)

“Most of the cases we see here are due to depression. It’s a big issue. Most people you will find they have depression in these communities.” (KII with healthcare provider, Kaloleni)

Despite participants revealing that there were cases of dementia in their communities, we learnt from healthcare providers that these patients rarely sought care in hospitals or nearby health centers. In addition, healthcare providers did not have the requisite knowledge or capacity to diagnose, manage or treat people living with dementia. They primarily focused in treating conditions like depression and substance abuse, which were perceived to be more common in Kilifi, compared to dementia.

“Yes, most of the senior population do not go to the hospital, but we have seen some cases of Alzheimer’s that presented themselves to the clinic. However, I don’t have the exact numbers.” (KII with a healthcare provider, Kilifi County)

“Many people that we see have depression. Depression is the highest. But we also have schizophrenia, psychosis, and substance use. Also, we have some cases of dementia, but they are not many that come to hospital.” (KII with a psychiatrist, Kilifi County)

Theme 2: perceived causes of dementia

Old age was said to be the main cause of dementia. It was noted that symptoms of cognitive decline such as loss of memory emanated from the natural process of aging.

“Because they were fine at one particular time, and then all this changed as they were getting older. So, we could not pick what could be the cause because I would, I would’ve understood it better if it’s something they had picked it, right from a young age. I guess the main cause is the aging process.” (Healthcare provider, Rabai)

“We normally assume its old age. You know this society thinks that when you are old, the memory decreases.” (Community Health Volunteer, Rabai)

“So, for Dementia, its associated with old age and aging seems to be the cause of Dementia.” (Key informant interview, policy maker)

Dementia was perceived to be a natural aging disease. Because elderly people suspected to have dementia did not manifest physical symptoms associated with the disease, they were not perceived as “sick” or “ill”, but to be undergoing a natural aging process.

“Now, people tend to assume that if the memory has deteriorated and he has gone back to behaving as a child and now they assume this is normal and there is no need of him being sent to the hospital, they think that it is a normal thing.” (FGD with community health volunteers, Rabai)

Participants also noted that substance abuse and everyday stressors such as socio-economic stress were other potential causes of dementia as described below.

“The thing that is common especially among the elderly is that of alcohol, and some of them also smoke bhang. This is because of the everyday challenges that people go through. Lack of food and jobs makes people use drugs. In fact, some of them have smoked bhang for long, since they were youths. With these drugs, it will obviously affect their brain. They may end up developing dementia. And now because someone is addicted to the drug, quitting is not easy.” (FGD with community health volunteers, Rabai)

“Even the way we have said that these people are using these alcoholic beverages, you will see if a person continues to use these alcoholic beverages, and if he is above the age of forty all the way to fifty or sixty, the brain activity will also change, it will deteriorate.” (KII Traditional healers, Kaloleni)

Moreover, healthcare providers associated dementia with mental illnesses such as depression and trauma, human immunodeficiency virus (HIV) and cardiovascular diseases such as diabetes or heart disease. These diseases were said to trigger long term stress in individuals, which could result in a dementia diagnosed in old age. For instance, some participants explained the sequential observations they had seen from people being depressed to developing neurodegenerative conditions such as dementia.

“But all those behaviors of dementia can be because of stress or some hallucinations, some is depression”. (FGD with healthcare providers, Rabai)

“I think trauma, thinking too much, may be a cause of Dementia. People get traumatized, stressed, and some end up getting dementia.” (FGD with community leaders, Kaloleni)

“Most of them, I tend to say that they suffer from psychosomatic disorders. Our long-term clients with chronic diseases, like the ones who are having HIV, they had a lot of depression, and this can cause memory issues and dementia at the end.” (KII with a healthcare provider, Kilifi)

Interviews and discussions with community members also associated behavioral aspects of dementia with witchcraft. In this case, elderly people who had neurodegenerative conditions were believed to have been bewitched or cursed, *“Okay, there are myths about dementia, people believe*

that a person with dementia may have been bewitched or cursed.” (KII healthcare provider Kaloleni)

Theme 3: community perceptions of dementia

Symptoms and presentation of dementia. Dementia was commonly described in terms of its symptoms such as memory loss or forgetfulness. However, forgetfulness was well understood and perceived as a normal process of ageing. In fact, some participants articulated that “we all forget” when describing forgetfulness, and narrated situations which entailed patients forgetting people’s names, place of residence, and doing routine activities such as grooming themselves.

“But there are many of them, and you can even be sitting with him or her here and then you leave and when you return, he starts saying who are you? Where are you from? Now you will start wondering how is this possible, ‘it’s me grandpa?’ It’s me.” And he is like “What is your name?” (KII with Community Health Volunteer, Rabai)

“Since my grandmother reached 89 years old, the situation of forgetfulness has affected her a lot. So, if she sends you something right now, later you come with it she has forgotten what she sent you”. (FGD with Faith healers, Kaloleni)

“I think mostly there are those who will forget events. You find that they can, you go there today, but tomorrow you go they don’t even recognize you. Or in other words, they don’t know what’s happening around them kind of. I’ve come across some of those ones here who kind of you go today, tomorrow you go again, and they don’t recognize that you were there the day before. So yeah, it’s happening.” (KII with a researcher working in Kilifi)

Participants also noted that elderly people suspected of having dementia were quite irritable. Some were stressed and seemed frustrated. A few demonstrated anti-social behaviors such as self-isolation and, in some cases, some ended up having suicidal tendencies:

“You may find he [patient] is stressed due to overthinking, and then he becomes angry, and his temper rises fast. Some are unkempt or have low self-esteem. Some are anti-social which may also lead to suicidal thoughts.” (FGD with healthcare providers, Kaloleni)

Most importantly, some participants described some elderly people suspected to have dementia as having lost hearing and visual capabilities as described below:

“What I have personally noticed is that there are those who have memory loss, and others lose their eyesight, that is, they cannot see clearly and when you speak that is when they recognize you, they know this is my grandson, but they

probably do not see. But there are those who see perfectly well but their hearing is also a problem”. (KII with a community health volunteer, Rabai)

Labeling of people with dementia. Our findings show that elderly people with dementia related characteristics (described above) were labeled using derogatory words and language. Some of these labels were linked to cultural beliefs and stigma associated with “memory loss” as well as the community lacking knowledge of dementia. Words such as “neurological deficit” and “lost network”- meaning that the patients are not cognitively active or functional, were commonly used to label people suspected to live with dementia.

“It’s like they have lost their network [symbolizing memory loss]. If he is told something today, he will not remember the day after tomorrow. Let’s say for example we all wake up at home, maybe I’ll greet him at home, we were all there yesterday...and if we meet again today, he will be like ‘who are you?’ (FGD with community health volunteers, Rabai)

“Cause dementia, you will call it psycho neurological, cause there’s a neurological deficit, at the same time it could be psychiatric.” (KII with healthcare provider, Rabai)

In addition, community members perceived dementia as a mental illness and used words such as “*Mwendawazimu*” meaning a mad person or ‘crazy person’, which was also stigmatizing these people:

“There is stress, there is insanity, there is craziness, there is madness [mwendawazimu]. In other words, when the mind is disturbed, it is as if he [patient] has smoked marijuana, he does not understand what he is doing. That is how I see dementia” (KII with a Faith healer, Kaloleni)

Secondly, participants provided labels such as they (elderly people suspected to have dementia) are “behaving as a child.” In one FGD, a discussant said; *“They are perceived to be like a child because of their behavior, like those of children. They get angry fast but also forget fast. Even if you do something wrong to them, they will forget it.”* (FGD with Faith healers, Rabai). Another discussant in a different FGD said: *“They mostly behave like a child. That is, it is as if he has forgotten everything completely.”* (FGD with community health volunteers, Kaloleni). This is again due to lack of understanding of the illness and stigmatizing behaviors linked to dementia.

Fourth, some community members revealed that elderly people suspected to be living with dementia were perceived to be witches due to bizarre behaviors linked to forgetfulness or losing their way back home. A psychologist working in one health facility in Kilifi narrated that:

"We are looking at why this wazee [the elderly] being killed, and mostly they're being killed because of dementia. Because at certain age, the structure of wazees [elderly people's] house...they normally build houses, and the toilet is very far from their house. So, this mzee [older person] perhaps would just come out in the night and maybe feel like to go for the call of nature. And he'll keep on looking where the toilet is. And after getting the toilet, he finishes the call of nature'. Then after that, he's now looking, going back to the house. So, he'll keep on meandering, meandering, trying to figure out where the house is. This can take long up to morning, and people will say, this is a witch. So, this is something that Kilifi County, they do not have that knowledge that these elderly people may not be witches but be suffering from dementia" (KII with a healthcare provider, Kilifi County)

Another participant, a psychologist echoed the same in a separate interview, and noted that community members largely associated "forgetfulness" and "memory deterioration" with witchcraft. She stated that "the elderly people with dementia were not necessarily witches; *"they are men and the women who are so old are suffering from dementia, not that they're witches"*. Given the above labeling towards people suspected of having dementia, most families or individuals were reluctant to publicly talk about their conditions for fear of being stigmatized. This was another contributing factor to them not seeking healthcare in the first place: *"Many people are unwilling to discuss the illness openly in fear that they will be labelled as 'crazy'".* (FGD with community health volunteers, Kaloleni)

Theme 4: challenges experienced by elderly suspected to have dementia in Kilifi County

Isolation and neglect. While discussing about the risks that elderly populations suspected to have dementia face in Kaloleni and Rabai communities, almost all participants revealed that these populations were exposed to stigma and social isolation – in part due to limited or poor community understanding of dementia and stigma associated with it. The isolation was both self-isolation as well as isolation by close family or community members.

"Some elderly people are told they are witches, the children run away and leave them at home. They end up being isolated by family and community at large". (FGD with healthcare providers, Kaloleni)

"...and the elderly with dementia they're neglected. Most of the people don't want to associate with it [dementia] because they know these people are poor. Number two, because of that, it makes them more vulnerable to attacks." (KII with Faith healer, Rabai)

Others mentioned that some family members would discriminate against the elderly person, lock them up in the

house, or not take care of their medical, social, financial, or nutritional needs either due to lack of knowledge on how to support the elderly persons, or as a way of avoiding community stigma directed towards the family. As a result, it was revealed that people with dementia tend to participate less in community activities or engage in social functions. Some are lynched as exemplified here:

"They stay at home most of the time. They are isolated from the community or community activities like church. If it's a woman, she will not enjoy the women group meetings because of her illness." (KII healthcare worker in Rabai).

"They die of loneliness. Children have abandoned them. Some are accused of being witches and they are lynched." (FGD with community health volunteers, Kaloleni)

Killing of the elderly suspected to have dementia. The elderly perceived to have bizarre behaviors were largely suspected to be witches and were killed. This was described by many participants as an area of concern - including those working in healthcare facilities as well as community members:

"They targeted very, very old people. Both male and female. And that's why they are dying. They're killed. You can't pass a day within two to three days, an old man was killed in, at somewhere because people thought that he's a witch or a traditional healer." (KII with a psychologist, Kilifi County)

"The elderly between the ages of 45 and 70 who are mentally disturbed because they are often suspected of being witches. They are suspected of being a witch although of late cases have decreased, but in the past, they were being killed so they had the problem of what will happen next. What if I am the next one to be killed? I should do something like that so that it messes a lot with their brains." (FGD with healthcare providers, Kaloleni)

The issue of elderly killings had become an area of concern especially amongst health care providers and policy makers. An interview with a key policy maker indicated that other than being perceived to be witches, there were contentious issues such as grabbing land for the elderly people by the younger people. As such, elderly were killed to take over their land. To address the elderly killings in the county, one of the policy makers we interviewed in Kilifi narrated that:

"...Because of this you know we have our home for the elderly in somewhere in Vitengeni, because there is a time they were being attacked by their family members that they were witches, they have become witch-doctors but the, the whole issue we've realized was not an issue of being a "wachawi" [witches] but just because the young people want to take

over the land, yeah so we have addressed that in like the document; to deal with the elderly killings". (KII with a policy maker, Kilifi County)

Similar sentiments were echoed by a key informant working in a research institution in Kilifi:

"Some people think it is also mainly because of competition like for resources. People want to inherit, and you become a stumbling block. Or they want to sell that piece of land and you are a stumbling block. So, they might want to kill an elderly person so they can have the, their possessions and use it the way they want." (KII with a Researcher working in Kilifi)

Lack of social and medical support. Limited to lack of social support for the elderly people suspected to have dementia was discussed. While some families supported their loved ones, other families did not offer the patients social support. This was especially in the context of economic hardships in Kilifi where family members left the elderly and children behind as they went out the whole day to look for jobs or income to put food on the table:

"For many families, these people become isolated in terms of kind of neglect because as you know now when you are in that condition, you would want to have somebody to care for you throughout. But I think you don't see that most often in terms of maybe dedicated person who cares for them. So, people would go about their businesses maybe and converge back in the afternoon or in the evening. I wouldn't say they're getting optimal care in terms of having someone to look after them as you would expect. But that's also it is dependent on the families where they come from. You have some families maybe where we find that there's good kind of network for support system, but others do not really have support systems for, for such. I think, yeah, it's not really a good condition to have in a community like this." (KII, Researcher from Kaloleni-Rabai)

There was demand for social and medical care for people suspected of having dementia, which was generally lacking in Kaloleni and Rabai sub-counties. Access to social or medical care was dependent on family background- in terms of knowledge or understanding of dementia and access to care:

"But that's also it is dependent on the families where they come from. You have some families maybe where we find that there's good kind of network for support system, but others do not really have support systems for, for such. I think, yeah, it's not really a good condition to have in a community like this. Yeah." (KII, Researcher, Kaloleni-Rabai)

Moreover, when symptoms of cognitive decline were assumed to emanate from normal aging, people suspected

to have dementia did not receive medical and social support when in need.

"We mostly assume its normal aging. They are not sick, they are okay, the only thing is that they can't remember things. So, these people are not sent to the hospital because we assume its old age." (FGD with community health volunteers, Rabai)

Recommendations

First, lack of knowledge about dementia in this context was evident. Participants recommended a need to conduct community sensitization and advocacy on dementia as a way of reducing stigma and discrimination of the elderly people with dementia and enhancing protection of the elderly people:

"The main issue is that communities do not know anything about dementia, they think they are witches. There is a need to educate communities and families about dementia. This will be one way of ensuring the elderly are not mistreated or killed. This can also help the communities to work with the families in taking care of the patients." (KII healthcare provider, Kaloleni)

Second, due to the threats that elderly people suspected to have dementia were exposed to, participants especially policy makers and health care providers suggested a need for the County government of Kilifi to invest in social pension schemes and insurance cover for the elderly. This was said to be one way to enhance access to medical care by individuals with dementia.

"Money for the elderly. Those who are elderly should also be medically checked. Medical care for the elderly: So, at least if there was that they have that cover if it is NHIF, whatever, they can access medical care even if his child is not helping him, but yes there is something that can sustain him, yeah. Then at least they should be sensitized." (FGD with healthcare workers, Kaloleni)

In addition, a need to develop local tools for diagnosis was said to be pertinent to increase early screening and care for patients with dementia:

"We should also increase scientific research on aging and health and develop and validate contextually relevant tools for predicting the risk for dementia to aid early diagnosis." (KII with a policy maker, Kilifi County)

"Have a study on aging and health in which we try to develop, adapt tools to investigate some of the factors that influence or are influenced by the aging process, principally how aging and associating factors influence health as people grow old in that setting." (KII with a researcher, Kilifi County).

Discussion

We sought to understand community understanding and perceptions about dementia in Kilifi County, a resource constrained rural setting in Kenya. The overarching finding was that residents of Kilifi County had a poor understanding of dementia and expressed misconceptions of the disease. People suspected to have dementia frequently faced stigmatization through derogatory labels such as “mad”, “crazy”, or “neurologically deficient.” Some were isolated from the community and were susceptible to violent attacks when symptoms of neurological decline such as forgetfulness or confusion were misconstrued as manifestations of witchcraft or curses. In what follows, we provide a summary of our findings along these domains: (a) knowledge and understanding of dementia (b) perceived causes of dementia, (c) community perceptions of dementia, and (d) elderly abuse of people suspected to have dementia, in relation to other studies.

While dementia appeared to be present in this community, most gatekeepers, especially those who did not have a medical background such as chiefs, assistant chiefs, and traditional healers, demonstrated a general lack of awareness about the condition. They found the term dementia complex and alien. In addition, in contrast to other neurological conditions such as epilepsy and mental health conditions such as depression that were well known and had Kiswahili and Giriama terms, they had not curated any local term for describing dementia. It was only after we described what the condition was and its common manifestations that they were able to recognize what dementia was and acknowledged that they had seen some cases in the community. The trend seems to be similar in other rural African communities.^{32,33} As such, to create dementia-friendly communities, we should prioritize developing programs for sensitizing rural African communities about the condition. Community workshops worked well in South Africa.³³ Moreover, training lay healthcare workers in dementia care and setting up community-based dementia management programs not only improved community sensitization efforts in south-western Uganda, but also surveillance and referral of people with dementia for care.³⁴

After describing what dementia was, we uncovered that while members of the community were aware of its common symptoms such as forgetfulness, disorientation and language difficulties and could link such symptoms with cognitive decline, the spirit of inclusivity and tolerance was not being extended to people with dementia. As we have discussed earlier, for example, there was no local term for describing dementia. Members of the community commonly used stigmatizing, discriminatory, underestimating and minimizing language and terms such as “neurologically deficient” and individuals who had “lost network,” to describe people with dementia. Other members of the community used derogatory words such

as “mad” and “crazy” to describe these individuals, which not only dehumanized them but has also been shown to predispose people living with dementia to neglect and discrimination in other settings.³⁵ While this could be attributed to the general lack of awareness about dementia in this rural community, such labels reinforce cultural stigma and misconceptions around dementia.^{16,17} Patterns of social neglect and discrimination also hasten cognitive and physical demise, given the importance of social engagement, physical activity, cognitive enrichment, and nutrition in slowing decline and improving overall quality of life of people with dementia.³⁶

In some cases, manifestation of common symptoms of cognitive decline such as forgetfulness, disorganization, communication problems, and disorientation were not considered unusual as people grew older. Some respondents considered manifestation of such symptoms a consequence of the natural process of aging, which was also ranked among the main causes of dementia, and not an underlying disease. Apart from lacking information about dementia, we postulate that such regressive myths around dementia, as has been demonstrated in other African settings,^{22,33} could be a contributing factor. In addition, because the Kilifi County administration has not put in place local and communal mechanisms for supporting the elderly or sensitizing members of the community on dementia, it might be contributing indirectly to the trauma people with dementia are subjected to when such misconceptions lead to neglect of medical treatment and expose them to secondary complications such as stress, frustration, anti-social behavior, or suicidal behavior in some cases. While such regressive myths and misconceptions could be lower in some urban Kenyan Counties such as Nairobi where patients receive significantly better neurological care, we do not have data to support this argument. This will be investigated in the follow up study.

Prior studies in South Africa showed that elderly individuals who exhibit peculiar and or abnormal traits and behaviors, as per community standards, are often thought to be witches or cursed.^{14,18} Even when such individuals have been diagnosed with dementia, the perception that they are dangerous to the community, are prone to violence, and therefore should be avoided persists.³³ The association of symptoms of cognitive decline with witchcraft also instills fear of people with dementia¹⁹ and can lead to affected individuals being ostracized from communities and predisposed to violent attacks.¹⁶ Here, we report similar findings in Kaloleni and Rabai sub-counties of Kenya. Symptoms of cognitive decline were associated with supernatural forces such as witchcraft and curses, predisposing the affected to neglect by their family members or the community. These perceptions were motivated by a combination of factors such as ignorance (or lack of information) and greed for wealth. Incidental cases were associated with culture. For example, because most houses in

Kaloleni and Rabai sub counties have outdoor toilets, elderly individuals with dementia who use such facilities at night can become disoriented and wander into other people's homesteads where they are labeled as witches or sorcerers and killed. Analyses of other witch-burning cases from Kisii County and other areas of Kilifi County have also revealed a likely link between elder abuse and resource and social conflicts. People are wrongfully accused for the deaths of their husbands or children, emboldening the community to label them as witches or sorcerers and disposes them assets such as land or kill them.^{37,38}

Addressing these threats to people with dementia necessitates the local and national government and other stakeholders to put in place community sensitization campaigns that could dispel dementia-related stigma and discrimination, dismiss the regressive beliefs or misconceptions that predispose people with dementia to violent attacks, and create community-based surveillance and support systems that could fast-track the diagnosis of dementia and referral of individuals with dementia for specialized care and support. This was not happening in Kilifi County.

We found limited to lack of social and medical support programs for people with dementia. Our respondents revealed that even in community healthcare facilities, healthcare providers lacked the knowledge or the necessary training in managing dementia. Concerns were also raised about the lack of access to neurologists and appropriate diagnostic tools, which could lead to delayed diagnosis and poor management of dementia as evidenced in other studies conducted in other rural contexts in Kenya.²² This calls for training of primary healthcare providers in rural areas to be able to screen and diagnose dementia cases. Similar approaches of trainings have been conducted elsewhere³⁴ and have enabled early screening and diagnosis. Along these lines, it is also important to ensure availability of diagnostic tools to enhance early screening and timely management of dementia.³⁹ Importantly, given the limited number of psychiatrists and neurologists in Kenya,⁴⁰ it will be crucial to train and work with informal caregivers such as community health promoters as a way of enhancing human resource for health in community settings. The approach of task sharing has been successful in increasing access to mental health care in other rural areas in Kenya and Uganda.^{34,41}

Research and policy implications

We need frameworks, policies, and programs for sensitizing members of the community about dementia, improving access to dementia care, and safeguarding the health, wellness, and safety of people with dementia in rural settings. We should also develop context-relevant diagnostic tools for dementia in such rural communities and tap into the

expertise of CHVs to roll out community-led screening and surveillance systems for dementia. It would also be useful to estimate the cost of inaction and the potential economic case for support to bolster the economy and profile the existing local dementia care practices in a larger study in the future.

Acknowledgments

This project would not have been possible without the generous devotion of time and energy of our 60 participants from Kaloleni-Rabai sub-counties and the larger Kilifi County. We are grateful for the hard work of Everline Onchari from BMI who helped with data coding for this project and Felix Agoi who supported field work mobilization. An extended appreciation goes to the County government of Kilifi for the continued support in research conducted in the region.

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Statements and declarations

Author contributions

Andrew Aballa (Conceptualization; Data curation; Investigation; Methodology; Writing – original draft; Writing – review & editing); Linda Khakali (Data curation; Formal analysis; Investigation; Writing – review & editing); Willie Njoroge (Data curation; Investigation; Writing – review & editing); Lucy W Kamau (Writing – review & editing); Zul Merali (Funding acquisition; Writing – review & editing); Edna N Bosire (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Writing – original draft; Writing – review & editing).

Data availability

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

Seed grant from the Aga Khan University's Brain and Mind Institute.

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