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# How dementia knowledge and experiences influence care and protection of people with dementia: Evidence from Lesotho

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#### Abstract

The objective of the study was to find out how knowledge and experience of dementia influenced communitybased care and protection of older persons with dementia. The study was conducted in Mafeteng Lesotho in 2020, using a qualitative research design underpinned by African humanistic philosophy. Data were collected using interviews and focus group discussions from 10 purposively selected caregivers of people with dementia and a convenience sample of 13 community members, respectively. Participants from both samples had adequate dementia knowledge. The findings indicated that dementia knowledge and care experience positively influenced care of people with dementia by both families and communities. To promote community care and protection of people with dementia therefore, the Ministry of Social Development Lesotho is called upon to provide dementia education and to incorporate caregivers of people with dementia in the education programs. The benefit of incorporating people with dementia in dementia education is that voices of people with dementia would add weight to the programs while boosting self-worth of those with dementia.

#### Key words

African research philosophy; community care; older persons; dementia; Lesotho

#### **Key points**

- 1. Dementia knowledge and encounters with people with dementia improve compassion, care, and protection for people with dementia.
- 2. Dementia sensitisation campaigns can benefit from caregivers' accounts of caring for people with dementia.
- 3. Community care of people with dementia can be strengthened by involving people with dementia in dementia sensitisation campaigns.
- 4. Lesotho's dementia support and education campaign has strong prospects but, it should be intensified.



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# Introduction

Dementia symptoms have been associated with witchcraft among Africans including Basotho, leading to widespread human rights violations against older persons. In response, Lesotho Ministry of Social Development initiated a countrywide dementia support and education campaign targeted at families and community members. The campaign, which started in 2017, entails targeted messaging for all population sectors from in-school youth, out-of-school youth, community leaders and adults. The campaign is yet to be evaluated. The objective of this study was therefore to examine dementia knowledge in Lesotho as well as how such knowledge and associated experiences could impact the welfare of people with dementia in in Lesotho. The rationale` for the study was to inform ongoing dementia care and protection initiatives in the country. This article briefly discusses dementia literature, study methodology and findings, then concludes by advancing recommendations for strengthening of prevailing care and protection initiatives of older people at community level.

Basotho are natives of Lesotho while Sesotho refers to Basotho's vernacular and culture. The previous version of diagnostic and statistical manual of mental disorders, DSM-IV, described dementia as a syndrome of neurocognitive diseases affecting key functions of the brain and common among older persons. The manual further cited generalised and specified forgetfulness, mood swings, as well as compromised ability for organized, effective reasoning as some of dementia identifiers. Dementia can also compromise effective communication. In its advanced stages, the DSM-IV indicated that dementia symptoms range from delirium, agitation, aggression, wandering, sexual disinhibition to hallucinations and delusions (Foley and Swanwick, 2014; Harland et al., 2017; Pathak, 2018). Dementia symptoms are distinct from those of normal aging and include considerable change in behavior such as "coursing" of social skills (Pathak, 2018). The condition compromises and endangers the lives of afflicted people along with that of those around them. Furthermore, the current DSM-V distinguishes 16 categories of neurocognitive diseases (NCD) including NCD due to Alzheimer's, vascular NCD, substance induced NCD, and NCD due to HIV and/or other aetiologies. This article uses dementia to refer to all age and lifestyle related neurocognitive disorders.

# Social significance of dementia knowledge

Despite known dementia challenges characteristic to Africa, more dementia studies were conducted in developed countries (cf. Andrews et al., 2017; Ebert et al., 2019; Phillipson et al., 2019). Socioeconomic advancement of the developed countries notwithstanding, the studies revealed concerning knowledge gaps which compromised dementia care planning, health seeking, and caregiving (Andrews et al., 2017; Ebert et al., 2019). The trend is prevalent in Africa as well where lack of dementia knowledge is also associated with dementia stigma and injustice (Dhemba and Dhemba, 2015; Mugomeri et al., 2017; Soussou and Yogtiba, 2015; Spittel et al., 2019). For instance, Ghanaians without dementia knowledge were found to widely accuse people with dementia of witchcraft and to confine them to "witch-camps" where they could be beaten to death without penalty for their aggressors (Soussou and Yogtiba, 2015; Spittel et al., 2019). Such injustices have led to calls for dementia friendly communities whereby people affected and afflicted with dementia assume the responsibility for educating



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communities, an approach which holds prospects of improving self-esteem of people with dementia (Soussou and Yogtiba, 2015; Phillipson et al., 2019). Thus indicated, among other service requirements, was healthcare training focusing on community dementia-appreciation in addition to traditional biomedical knowledge (Andrews et al., 2017; Ebert et al., 2019). The authors called for innovative strategies for experiential community education programs rather than the widely practiced public lectures (Andrews et al., 2017; Ebert et al., 2019).

# Philosophical underpinning of the study

African humanistic philosophy was found appropriate for the study on account of the study's community-focused nature and because dementia has been reported to elicit intense community responses in Lesotho and other parts of Africa (Kaunda, 1966; 1973; Musisi, 2015; Nwakasi, 2019; Spittel et al., 2019; Sossou and Yogtiba, 2012). The central premise of African humanistic philosophy is recognition of both the value and vulnerability of older persons, particularly older Africans (Kaunda, 1966). To this end, the philosophy charges African communities to rally together to care for and protect older persons while stressing that no older person should be relegated to society's periphery or subjected to any avoidable suffering (Kaunda, 1966). Against the fore-cited principles, the theory's proponent considered care institutions, for instance, unnecessary impositions onto communities with otherwise adequate social structures to care for their own (Kaunda, 1966; 1973). While the theory holds considerable merit with regards to African communities' potential for older persons' care and protection, it ought to be recognised that factors such as family nuclearization and monetisation of almost all societal transactions may work against communities' good intentions to care for their own (Dhemba, 2013; Dhemba and Dhemba, 2015; Manyeli, 2021; Manyeli et al., 2023; Manyeli and Tanga 2012; Thabane et al., 2019). With regards to older persons particularly, belief in supernatural paradigms and inadequate knowledge of neurocognitive diseases which commonly affect the mentioned population further undermine African communities' openness to caring for older persons (Spittel et al., 2019). That notwithstanding, African communities' inherent strengths with regards to older persons' care ought to be recognised and harnessed where possible (Dhemba and Dhemba, 2015; Manyeli et al., 2023; Mugomeri et al., 2017; Thabane et al., 2019).

# Methodology

In line with the above philosophy, the study took a qualitative approach using a narrative design (Brancati, 2018). Data were collected using interviews and focus group discussions from a purposive sample of 10 caregivers of people with dementia symptoms as well as a convenience sample of 13 participants organised into two focus groups (Brancati, 2018). Among the 23 people who participated, 4 caregivers confirmed that they had received family support from Lesotho Ministry of Social Development while 1 community member from the focus groups said they had attended a dementia sensitisation public meeting. Interviews were conducted in Matelile, Ha-Motanyane, Ts'a-Kholo, Likhoele, Wepener Road, Hospital Area, Matholeng, and Likoung in the Mafeteng Urban Area while focus group discussions were conducted in Ha-Motanyane and Matholeng.



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The rationale` for selecting caregivers of those with dementia symptoms without a confirmed clinical diagnosis was because it was anticipated that most of the people with symptoms of dementia might not have been clinically diagnosed on account of both ignorance of the condition along with inadequacy of psychiatric health services in Lesotho. Secondly, caregivers, not the concerned older people, were interviewed because it was reasoned that the older people's compromised memory and communication capacity could work against effective data collection. Additionally, the study objective was on care giving therefore it was necessary to involve caregivers.

#### Implementation of the study

The study was implemented through the following three stages between November 2019 and February 2020: seeking gatekeeper permission and introduction to prospective participants, participant recruitment and selection, and data collection, which are discussed in turn subsequently.

#### Stage One: Seeking gatekeeper permission and introduction to prospective participants

Subsequent to introduction and gatekeeper permission, chiefs provided 24 names of older people in the community, their caregivers, and addresses, the second author visited 19 of 24 received addresses to explain the study and invite caregivers to participate. Seventeen of the 19 visited prospective participants were caring for older people who met the criteria for possible dementia diagnosis as outlined in the DSM-V, thus meeting criteria for inclusion in the study. Fifteen of those who met the criteria were employed and 2 were staying at home. The second author left her telephone contact details at the 15 addresses at which caregivers were at work with a request for caregivers to contact her, explaining the purpose for such communication. Twelve of the 15 addressees called or sent written telephone messages to the author.

#### Stage Two: Participant recruitment and selection

The two caregivers who were found at their homes were requested to participate after consent seeking and detailed explanation of purpose and process of the study. They were then requested to respond to a 6-point checklist of dementia symptoms and duration. Both participants gave responses indicating that people in their care met the criteria for dementia diagnosis.

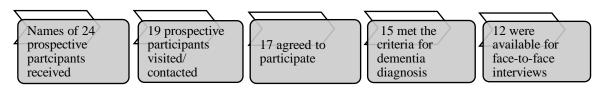
In addition to the 2 caregivers found at their homes and upon the first meeting, the 12 prospective participants mentioned under stage one who called or messaged were reminded why they had been visited and requested to give verbal consent to participate in the study. This was done on the telephone. They were then requested, on the telephone, to respond to a 6-point checklist of dementia symptoms and duration as listed in the manual to determine their eligibility to participate. Ten of the 12 caregivers who were contacted telephonically gave responses which suggested that the older persons in their care met the criteria for dementia diagnosis and agreed to participate. These were requested for face-to-face interviews at convenient times to them and interview dates were scheduled. Eight of the 10 prospective participants who made interview appointments were available on scheduled interview dates.



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This led to a total of 10 interviews conducted with caregivers. The recruitment and selection stages are illustrated on figure 1.

Figure 1: Stages of recruitment of sample 1 participants



# Stage Three: Data collection

Data collection took place for about a month in January and February 2020. Lesotho imposed covid-19 movement restrictions from April 2020 therefore data collection took place before such restrictions.

#### Interviews

Two caregivers found at their homes during participant recruitment and selection were interviewed on the same day. Further, 8 of the prospective participants who were contacted by telephone were met at their homes or workplaces for interviewing at scheduled times. All data were collected using vernacular and it was audio-recorded. All participants were advised that they could withdraw their participation at any point in the study and that there would be no direct rewards for participation. Interviews took 1 hour to 1 hour 30 minutes each.

# Focus group discussions

Like sample 1 participants, prospective sample 2 participants were requested to respond to a 6point checklist of dementia symptoms as listed in the DSM-V to determine their eligibility to participate. The rationale` for the 6-point checklist was to establish whether the prospective participants had encountered persons they suspected to have dementia. These were then requested to grant written consent to participate in the study and organised into focus groups when they were found. Both focus groups took place on Sundays when youth could be found with free time either walking from churches or just standing along the streets or by business centres. The focus group discussions lasted about 2 hours each. There were no direct rewards for participating in focus group discussions.

# Trustworthiness and reliability of research findings

Criteria for inclusion of caregivers (Sample 1) to the study was a minimum of six months' direct experience caring for and living fulltime with people aged 60 years old and above who presented at least four dementia symptoms as listed in the DSM-V. Secondly, any community member (Sample 2) who knew of another community member with four dementia symptoms as listed in the same manual could participate in the study's focus group discussions. All participants were adults. Data were collected by the second author. Trustworthiness and reliability checks for the study were triangulation, journaling, and member checks. For triangulation, data were collected from 2 samples using different data collection methods.



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Secondly, a list of prospective participants, appointments, and criteria determination were documented by the second author and read by the first author for input and ongoing guidance on implementation. Thirdly, two transcripts each were returned to caregivers and community members who participated for checking.

#### Findings

# Demographic information of people with dementia whose caregivers participated in the study

Ages of people with the above-described range of dementia symptoms whose caregivers participated ranged from 67 years to 87 years old. One was between the ages 60 and 69, four were between the ages 70 and 79 and five were between the ages 80 and 87. Eight of the caregivers who participated were female while two were male. Three of the caregivers were daughters of people with dementia, three others were their granddaughters, two were grandsons, one was a granddaughter in law, one a daughter in law. Eight Sample 2 participants were male while 5 were female. Below, sample 1 participants, who are labelled CG, were caregivers while sample 2 participants who were community members are labelled CM.

# Dementia knowledge

The following themes which emerged from the data are discussed in this section: knowledge of dementia-characteristic behaviour, knowledge of population which can be afflicted by dementia, and knowledge of dementia causes.

#### Knowledge of dementia-characteristic behaviour

Both caregivers (CG) and community members (CM) had adequate knowledge of dementiacharacteristic behaviour. Participants in both samples mentioned forgetfulness as a dementiacharacteristic behaviour adding that people with dementia forgot things which they had learnt, heard, or read. Some Sample 2 participants were quoted as saying:

"From what I have learned, [dementia] is forgetfulness." (CM1)

"What I have learned is that [people with dementia] forget almost everything." (CM4)

"[Dementia] is when people often forget things that they knew, heard, or read about." (CM7)

Knowledge of population which can be afflicted by dementia

Some Sample 2 participants (CM) had the impression that dementia affected older females only, more so those who lived alone, while others understood that it could affect both sexes as well as people of all ages.

"It affects older persons, both male and female." (CM1)

"It especially affects female older people who live alone." (CM4)

*"I think there is a problem with their brain function, especially as they grow older." (CM5)* 



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"This disorder is for older persons. Their brains tire and [older persons] start doings things that are out of character. This is caused by aging." (CM6)

Only one Sample 2 participant mentioned that dementia could afflict adults outside the older population category.

"I know that when people get older, their brains wear out. I could say they suffer from some sort of memory loss. It is however not just them. I too can also get that disorder." (CM9)

Knowledge of dementia causes

Sample 1 participants (CG) said dementia was a factor of age coupled with traumatic life experiences while some attributed the condition to supernatural factors citing *"making enemies during adult years"* as well as *"Basotho's bad heartedness"* as some of its probable causes. Sample 2 participants (CM) on the other hand, pointed at excessive alcohol use and aging as factors associable with dementia. Their responses included:

"I think they brought it on to themselves. These people drink a lot [of liquor], they do not eat right so their brains will wear out. They do not only suffer from dementia, but they present many health challenges brought on by their past [unhealthy] habits." (CM6)

"Dementia is a natural process of aging. When people age, they will have dementia." (CM8)

"Basotho are bad-hearted. Especially when you do better than them. My mother was not wealthy. But her business could support our family. [Money from the business] raised my siblings and I. So maybe they did something to her... we don't know (shrugging her shoulders)." (CG2)

"It is [because of] the age. My grandfather is very old. He has seen many things. Some of them even unsettling/traumatic." (CG6)

"But I say: my grandfather brought this to himself. He was very careless with his life, made many enemies. Maybe this is God's way of punishing him." (CG8)

#### Dementia experiences

Sample 1 participants (CG) said they had noticed forgetfulness, wandering, delusions, and aggression in those in their care causing the caregivers to associate the emerging behaviours with dementia. The themes are discussed subsequently.

#### Forgetfulness by family members with dementia

Sample 1 participants said they had noticed concerning levels of forgetfulness in people in their care.

"In my mother's case, the problem is with the memory part of the brain. Her memory does not serve her right at all. She is literally living in the past. She does something



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now and when questioned about it she says she did no such thing, or say something but a few minutes later, deny having said it. She thinks she is still 20 years old." (CG1)

"Mm.mm, my grandmother has this thing of being forgetful. For instance, she forgets everything and everyone. We live with her here, but she forgets our names completely. She can even forget the names of her other children. Sometimes she even says we should leave her house." (CG6)

Wandering, delusional and aggressive behaviour, as well as incoherent speech by family members with dementia

In addition to forgetfulness, almost all sample 1 participants (CG) narrated experiences of family members with delusions as well as aggressive behaviour and language. Some said their family members with dementia "lived in their world/the past" while others reported that they talked to themselves:

"My mother does unusual things. Sometimes I think it is because she is getting old. I will just be surprised to see her dressed in her shiny (smart/dress-up) outfit with a matching hat and her in-door shoes for no reason." (CG2)

"Apart from constantly being forgetful, she started acting out of character. She would talk to herself, and sometimes at night she would stand by the window and shout that the police should help her as she was held against her will." (CG3)

"She wanders around and gets lost a lot. For instance, she will leave the house like she's, like maybe, going to the toilet (which is a standalone structure outside the house), only for me to realise when she takes longer than she should that maybe she did not go to the toilet. That happened several times before I figured that I should watch her when she goes outside. It is also very hard to make meaning of her speech, worst part is that I would really be needing her to talk to me and make sense." (CG4)

"She is forgetful. Also, she started behaving in ways that she did not behave before. She tells weird, unreal stories and accuses us of plotting to hurt her, take her away or take her things away. I was there most of her life. I know some of her stories are just ... no (shaking her head)." (CG5)

"[My grandfather's] behaviour is surprising/confusing. You can tell that he is confused, or it is as if he is leaving in his own world. Sometimes I think it is because he is getting old. He could just wake up one day asking us who we are, what we want, and talking about his late wife as if [his wife] were still alive. He would tell you he needs to get ready for work, which he has not been to since I was a child. Sometimes he sits there and just talks to himself like he is having a conversation with someone. One time he just insulted one of our neighbours without a reason. He can even insult neighbours' guests or anyone he sees [in the neighbour's yard]." (CG8)



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"Grandfather never forgets anything, especially money [although] he does present with some of the symptoms of dementia. He does unusual things, and he uses rather strong, somewhat profane language. He likes to shout at us. He shouts at everyone really. He has a short temper, but [he is] not forgetful." (CG9)

CG9 added that her grandfather's challenging behaviour could even stop her from either performing house chores as required or arriving at work on time, saying:

"Can you imagine, when [my grandfather] is [out] there insulting [the neighbours] would I be able to go outside to empty a basin/bucket of [dirty] water? Tell me. He wakes up very early, before I got to work. Sometimes even before I open the door to leave for work, I hear him shouting outside. You know, I have to wait for the people he is shouting at to walk past the house before I walk out. You will understand that they will expect me to call him to order. Call him to order? How? Who?" (CG9)

"[My grandfather] was once found in the early hours of the morning. He was dressed in his short sleeping trouser only. But I think it was approaching Summer. Around September/October. It was not that cold. But as you remember [at that time of the year], early morning is still chilly. That day my mother wanted to give up [taking care of him]. She wanted to send him back to his [other] son. Luckily, [community members] brought him home safe." (CG8)

# How dementia knowledge and experiences influenced care of people with dementia

The two samples made compassionate comments pertaining to care of people with dementia. Sample 1 participants (CG) said experiences of caring for family members with dementia had taught them helpful care strategies and improved their sense of humour while sample 2 participants (CM) advised people to be respectful, patient, and tolerant towards those with dementia.

"[I leant] to be patient. Taking care of [people with dementia] requires a lot of patience. [I also learnt] that they should not be allowed to do as they please or have everything they demand and that they should be treated like children. Everything that needs to be done when taking care of children is required by caregivers of people with dementia." (CG2)

"Being understanding with [my grandmother] helped me, I do not get frustrated when she does some of the things that irritate me because I know she is not well and is not doing any of those intentionally." (CG4)

"When my grandmother is in her moods, we just laugh at her. She gets irritated when she cannot find something and accuses everyone of hating her and taking or hiding her things from her. We can help her to find what she is looking for, but sometimes you will look for things in her room the whole day. [One moment] she's asking for her light blanket (tjale in Sesotho) [which she put away but forgot where]. When you find the light blanket, she asks about something else (exclamation of exasperation). You will have to look for it some other time. Or she will eventually locate it." (CG6)



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"People should be patient with [those with dementia]. [People with dementia] should be supported. Most importantly people should not embarrass [those with dementia] on social media, because that seems to be the tendency of many people these days." (CM4)

"[People in the community] should also stop their tendency of dealing with things that they do not understand, because according to me the only reason people burn and kill old people with dementia is because they do not understand what is happening, they lack knowledge thus act foolishly." (CM8)

"Yes. They should be patient with them, talk to them in a respectable manner." (CM10)

"I remember one elderly man in my village who used to walk round dressed in a funny woollen top: A long top with no trousers on. One day he went as far as the main road dressed like that. What [community members] can do is to help in situations like that is to guide the old man back home without embarrassing him. Also, the community should teach children about dementia, and make them aware who has it in the village so that they can help them when necessary." (CM11)

Like CG4 quoted under dementia experiences above, CG3 devised a care strategy informed by her experience.

"The most important thing I have to do is make sure that she cannot leave the house at night. I have noticed that she does not have much sleep at night. She becomes restless and wants to go outside. That is why she can even make those embarrassing shouts at night. So, I have to make sure that the doors are securely locked. [Make sure that] she cannot even leave the yard if she manages to leave the house. Despite everything, she is my mother, I love her. She raised us with love, and I will not abandon her." (CG3)

One of the caregivers reported that patience was not their strongest trait:

"It is hard taking care of a person with dementia. I am a very impatient person, so you can only imagine how I get when I get stressed and frustrated, patience really is something that I do not have." (CG1)

#### Discussion

# Dementia knowledge and experiences

Contrary to participants in Andrews et al. (2017) as well as Ebert et al.'s (2019) studies, Sample 1 (CG) and Sample 2 (CM) participants had adequate knowledge of dementia and its probable causes although it was incomprehensive (Foley and Swanwick, 2014; Harland et al., 2017; Pathak, 2018). The participants cited forgetfulness, older age, agitation, and wandering as some of the factors associable with dementia. The cited characteristics were consistent with DSM-IV and DSM-V dementia identifiers. Regarding dementia experiences, Sample 1 participants said they had noticed unusual behaviour among family members with dementia such as talking about the past as if it were the present, wandering, paranoia, and aggressive language towards family members and neighbours. Grandmothers 4 and 5, who were 78 and 83 years old, respectively, had been found in the community wandering and apparently unable to find their way back.



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Grandmother 5 was also reported to be paranoid and accused her family members of plotting against her. Grandfathers 8 and 9 were reported to use depletive language at most people around them including neighbours, without provocation. Sample 2 (CM) participants also reported noticing an older man walking in the community in contextually unusual clothing.

# How dementia knowledge and experiences influenced care of people with dementia

Among community members, dementia knowledge was associated with compassion and kindness for those with dementia and their families while experience of caring for family members with dementia equipped the caregivers with care strategies. Both samples seemed to appreciate the value and vulnerability of olde persons as advocated by Kauda (1966; 1973). For instance, sample 1 participants devised suitable care strategies for the older people. The findings resonate with Phillipson's et al's (2019) arguments that co-residing with people with dementia in communities promotes compassion and support towards them. CG2 and CG3's experiences had taught them to take measures to care for family members with dementia such as keeping premises securely locked to stop members with dementia from wandering outside during the night and being vigilant about members with caring for children, saying caregivers had to set limits.

The study further found Kaunda's (1966; 1973) denouncement of outsourced care of older persons concordant with Basotho's reality. For instance, the study did not find indication of dementia stigma or violation as noted in previous studies (Dhemba & Dhemba, 2015; Mugomeri et al., 2017; Soussou & Yogtiba, 2015). Instead, families and community members and chiefs were found to rally together to care for older people. This was attributable to the presence of people with dementia in communities and perhaps community realisation that the people with dementia were harmless (Phillipson et al., 2019). Thus, community presence of people with dementia was found to strengthen communities' capacity for care and protection of the older persons. It is contended therefore that when communities rather than institutions (Andrews et al., 2017; Ebert et al., 2019; Kaunda 1966; 1973; Phillipson et al., 2019).

# Recommendations

From the participants' accounts, the Ministry of Social Development's dementia support and education program had not reached a significant proportion of Mafeteng residents, calling for intensification of the program. It would also be helpful for the mentioned department to involve caregivers of people with dementia to share their experiences in the ongoing and planned dementia education programs. Such experiential information would inform community members who may encounter situations where they need to support people with dementia. Additionally, people with early-stage dementia, who can still communicate, may be incorporated in community sensitisation campaigns to inform community members how dementia affects behaviour. The interventions are applicable to community-based care of older persons throughout Africa.



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# Conclusion

Findings of this study depart from others in Africa in that dementia knowledge was prevalent among study participants in both samples. With the exception of one participant, dementia knowledge and care experiences had a positive influence on how people with dementia were cared for and protected by all. Hence, knowledge dissemination and advocacy are key to care and protection of older people with dementia in Lesotho. It was encouraging to discover that the Lesotho Ministry of Social Development as well as community chiefs appreciated the difficulties faced by families of people with dementia and were available to support and advocate for such families.



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