

# ‘It is stressful, almost every hour...’: Experiences of caring for people living with dementia in Kenya—An interpretive phenomenological approach

Dementia  
2021, Vol. 20(8) 2916–2932  
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DOI: 10.1177/14713012211022989  
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**Purity Mwendwa** 

UCD Centre for Interdisciplinary Research, Education and Innovation in Health Systems (UCD IRIS), School of Nursing, Midwifery & Health Systems, University College Dublin, Dublin, Ireland

**Elizabeth Mutunga**

Alzheimer's and Dementia Organisation Kenya (ADOK), Nairobi, Kenya

**Thilo Kroll and Aoife De Brún**

UCD Centre for Interdisciplinary Research, Education and Innovation in Health Systems (UCD IRIS), School of Nursing, Midwifery & Health Systems, University College Dublin, Dublin, Ireland

## Abstract

**Introduction:** As chronic conditions such as dementia become increasingly prevalent, the role of caregivers will become ever more critical. In the East African region, little is known about the experiences of caring for people living with dementia. This study aims to describe the views of being a caregiver, including day-to-day responsibilities and duties, determine the impact of caregiving and understand participants' experiences of supports available or required to facilitate caring for a person living with dementia in Kenya.

**Methods:** This was a qualitative study that employed an interpretative phenomenological analysis (IPA) approach. We used convenience sampling to identify study participants in three counties in Kenya. Participants were main caregivers for the family and hence included both families and paid caregivers. We recruited 10 caregivers to participate in the study (9 females and 1 male). Data were analysed manually following the IPA approach.

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## Corresponding author:

Purity Mwendwa, School of Nursing Midwifery and Health Systems, University College Dublin, B113 Health Sciences Centre, Belfield, Dublin 4 D04 V1W8, Ireland.

Email: [purity.mwendwa@ucd.ie](mailto:purity.mwendwa@ucd.ie)

**Results:** Three main themes emerged from the analysis: the personal experience of caregiving, supports to assist with caregiving and the perceived unmet care needs. The challenges experienced varied based on the support available to the caregiver, the number of years in the caregiving role and knowledge and skills related to providing care.

**Conclusion:** Our study shows that caring for a person living with dementia is an arduous experience, requiring significant mental and physical effort. The study highlights a general lack of knowledge and awareness of dementia among families, healthcare professionals and the general public. Training programmes for caregivers, including dementia care skills, educating healthcare practitioners and organising public awareness programmes to understand and accept dementia are urgently needed.

## Keywords

dementia, caregivers, interpretative phenomenological analysis, Eastern Africa, Kenya

## Background

As chronic conditions such as dementia become increasingly prevalent globally, the role of caregivers will become ever more important. Dementia is a term used to refer to various neurodegenerative conditions that cause damage to the brain, and Alzheimer's disease is considered one of the main causes (Barker et al., 2002). Global estimates forecast that by the year 2030, 75 million people will be living with dementia, and the greatest increase will be in low- and middle-income countries (LMIC) (Prince et al., 2015). Age is the most common risk factor for developing dementia, although it can develop at much younger ages (before the age of 65)—known as young-onset dementia (Alzheimer's Disease International & WHO, 2012). People living with dementia often develop problems with their memory, reasoning and communication, and the condition can impact their ability to carry out basic daily tasks. In sub-Saharan Africa (SSA), which is observing some of the fastest-growing rates of older people in the world (Kinsella & Phillips, 2005), the number of people living with dementia is projected to increase, particularly in the East African (EA) region (Guerchet et al., 2017). Based on the complex care needs that arise as dementia progresses and the increasing prevalence of dementia, this population's caring needs are likely to increase.

In the absence of comprehensive government supports and well-developed home care systems for older people in SSA, caregiving falls mainly on family members (Aboderin & Hoffman, 2015; Keating, 2011; Therborn, 2006). Caring for people living with dementia, in particular, can be challenging. Previous studies identify behavioural and emotional changes of the person living with dementia as particularly difficult for the caregiver to manage, resulting in emotional distress, conflict and difficulty providing care (Ivey et al., 2013). A decline in the caregiver's physical health (Roth et al., 2009), social isolation (Brodsky & Donkin, 2009) and financial burden (Brinda et al., 2014) have been reported. Many family members do not understand the condition, which is not helped by the fact that diagnostic services are largely non-existent (Dias et al., 2008; Patel & Prince, 2001). Typically, informal caregivers are female relatives (Asuquo & Akpan-Idiok, 2020) of middle age or spouses of the person diagnosed with dementia (Brodsky & Donkin, 2009) with no professional caregiving training (Etters et al., 2008). Studies conducted in the SSA context find that informal caregivers often have low education levels and lower incomes, factors that further increase the caregiver burden (Yakubu & Schutte, 2018). Most caregivers are forced to leave education or employment. It may affect their opportunity to run a self-sustaining business (e.g. market stall) or farm, especially in rural areas.

Social support (Ivey et al., 2013), knowledge and relevant information on dementia (Williams et al., 2014) may improve the ability of caregivers to cope.

Kenya is one of the countries in the EA region committed to the UN Agenda 2030 for sustainable development, which commits countries to 'leave no one behind' (United Nations, 2017). The country has approximately 46 million people, with 4.5% aged 60 and over (United Nations, Population Division (UNPD), 2015). The proportion of older people in Kenya is expected to increase to 9.6% by 2050 significantly. It appears to be one of the sharpest increases projected for countries in the EA region, after Rwanda (United Nations, Population Division (UNPD), 2015). Kenya has developed policy and legal responses, which include a national policy for older persons (NPOPA) (United Nations, Population Division (UNPD), 2015) and Kenya's new constitution (Republic of Kenya, 2010). They demand the government to implement measures that take into account the needs of older Kenyans. Under the new constitution (2010), Article 10(2)(b) states that the government has '...together with the family, the obligation to provide care and reasonable assistance to older persons'. To advance the health and well-being into old age, in line with sustainable development goal 3, the Ministry of Labour, Social Security and Strategic Plan (2013–2017) provides a plan that would strengthen those institutions offering services to older people (Ministry of Labour, S. S., 2014, p. 55). However, the plan does not offer any provisions supporting those who provide that care to older people at home (Aboderin & Owii, n.d.).

There is a notable lack of dementia in policy debates and research activities in SSA more generally. This is evidenced most clearly by the total lack of consideration of dementia or even ageing in the Africa Union Africa Health Strategy 2016–2030 (African Union, 2016). In terms of research, we know very little about the experiences and support needs of those who care for older people in this context (Aboderin & Owii, n.d.). The current study addresses this gap and aims to explore the experiences of caring for a person living with dementia in Kenya. The objectives were (a) to describe the views of being a caregiver, including caregivers' day-to-day responsibilities and duties; (b) to determine the impact of caregiving and (c) to understand participants' experiences of supports available or required to facilitate caregiving. Such evidence is needed to (i) help raise awareness about dementia and the profile of caregivers, (ii) inform the design and implementation of dementia policies and (iii) inform the design of culturally sensitive and acceptable supports and services for people living with dementia and their caregivers.

## Method

### Study setting

The study was conducted in three counties in Kenya–Nairobi, Laikipia and Meru. Nairobi is Kenya's capital city, and Nairobi County sits within Greater Nairobi, which comprises five of the 47 counties in the country. The county has a population of 4.4 million, 1.3% (58,265) aged 65+ (KNBS, 2019). Laikipia county, located in the central Rift Valley region, is mainly rural, with a population of 518,542, with 4.8% (25,029) aged 65+ (KNBS, 2019). Meru County (population 1.5 million) is situated to the east of Mount Kenya. Meru is one of the counties in the country with the highest number of people aged 65+ (5.6% (86,730) (KNBS, 2019). Kenya is a multilingual country. However, Swahili, the lingua franca and English are the official languages. Most older people in Kenya continue to remain active in society in the retirement age, contributing to food security through agricultural activities and the economy through small businesses running. Often, in particular women, older people take on the role of caring for younger children, especially orphans,

providing both social and material support regardless of their poverty levels and deprivation (Chepngeno-Langat et al., 2019).

### Study design

We employed interpretative phenomenological analysis (IPA) in this study. IPA focuses on the detailed examination of personal lived experience, the meaning of experience to participants and how participants make sense of that experience (Smith, 2011, p. 9). Information was gathered from participants through semi-structured interviewing.

### Sampling of participants

To identify families with a person living with dementia, we used convenience sampling (O’Haire et al., 2011) based on the researchers’ existing relationships with organisations supporting people living with dementia and caregivers. Participants were selected if they were the main caregivers for the family, and hence, this included both family members and those employed to provide care. Given the lack of evidence on this topic, past caregivers were also eligible to participate in the study.

Identifying and recruiting caregivers, particularly in rural locations where dementia is not well understood, can be challenging. Before the study, the first author (PM) invested about 6 months in 2019, liaising with caregiver support groups and organisations working with older people to promote the project. PM also gave talks in churches and met with community groups to gauge the study’s feasibility (Mwendwa, 2020). Following this outreach work, we recruited and interviewed 10 participants comprising a diverse group of caregivers (Table 1).

### Procedure

We conducted interviews in participants’ homes or in a location that was most suitable for the participant. In 5 of the 10 interviews conducted, the person living with dementia was present at the interview. The interview schedule guide was informed by previous studies (Gurayah, 2015) and acted as a guide with questions reflecting the aims and objectives of the study. Interviews were conducted in English or the local languages (Swahili or Kimeru) at participants’ request. All

**Table 1.** Demographic profile of participants.

Participant’s code	Age range	Gender	Years of caring	Relationship to the person living with dementia
P1	50–59	Female	10–14	Husband
P2 <sup>1</sup>	60–69	Female	5–9	Husband
P3	40–49	Female	5–9	Mother
P4	40–49	Female	0–4	Father
P5	60–69	Female	10–14	Husband
P6	60–69	Female	0–4	Husband
P7	50–59	Female	0–4	Mother
P8	40–49	Female	0–4	Paid caregiver
P9	40–49	Male	0–4	Paid caregiver
P10	60–69	Female	0–4	Husband

<sup>1</sup>Past caregiver.

interviews were audio-recorded and lasted between 45 and 60 min. The interviews were then transcribed and translated into English.

### *Data analysis*

The interview transcripts were analysed manually using the IPA analytic approach (Smith, 2011). The analysis of experiences is an interpretative activity on the part of the participant and the researcher in which ‘the participants are trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world’ (Smith & Osborn, 2003, p. 51). The approach has been used in a recent study to understand family caregivers’ experiences for people living with late-stage dementia (Dempsey et al., 2020).

For the current study, we adopted Smith et al. (2009) analytic framework in which transcripts were read and re-read to become as familiar as possible with the accounts. This form of analysis was iterative and involved a close interaction between the reader and the text. Emergent themes were then noted, and connections across emerging themes were identified, and the same process repeated for each transcript. Once each transcript was analysed, superordinate themes were identified based on particular quotes related to the research question.

## **Results**

### *Participant characteristics*

Participants included nine current caregivers and one past caregiver from three counties in Kenya.

Caring for a person living with dementia often presents an enormous burden to families and particularly the person involved in providing direct care. This study identified several challenges associated with caregiving in the home setting. These challenges varied based on the supports available, the number of years in the caregiving role and knowledge and skills related to providing care. Three superordinate themes supported by sub-themes emerged from our analysis: (1) the personal experience of caregiving (the emotional impact and self-regulation, practical or instrumental challenges), (2) supports to assist with caregiving (financial and material support, hired help) and (3) the perceived unmet care needs (lack of diagnosis and or misdiagnosis, lack of knowledge about dementia and dementia care skills, no emotional, instrumental or practical or financial support).

### *The personal experience of caregiving*

This section focuses on the sub-themes common to the participants’ descriptions of the caregiving experience. The personal experiences elicited key elements: caregivers’ negative emotional impact related to the grief-like experience of caregiving and the feeling of no longer living your own life. At the same time, participants also acknowledged the caregiving experience aspects that can be beneficial and rewarding.

### *Caring as a difficult job and grief-like experience*

Caregiving seemed an arduous experience, requiring significant mental and physical effort: There was a sense of anger and bitterness evident in caregivers’ responses linked to their current situation.

Challenging behaviours such as agitation and aggression made caregiving difficult, and these behaviours impacted other family members:

[] Like when this problem started, he was violent. Sooo.... you can imagine this person; you used to reason together, he can't reason now, he even wants you out, he is telling you he wants you out of this house.... he says, "I want you to go", But in your mind, you know that he is not well. (P1)

In some instances, the person living with dementia behaved in an inappropriate manner which was embarrassing and disturbing:

We might be seated here, and all of a sudden, she decides to relieve herself here, right in front of us. And sometimes I feel no... no... I cannot continue with this job. (P8)

There was a sense of hopelessness and despair evident among caregivers in all interviews, as one caregiver described:

My life is very difficult. That is what I can say compared to the time when he was not sick. Because there are times, I think a lot and see as if my life is coming to an end. (P6)

There was a sense of an ongoing grief-like experience for those caring for a spouse or a parent. Some felt at a loss as they could do nothing to improve the situation:

[]Another challenge is realising that you are losing this person every day, and once you lose a part of them, it will never come back. You have to deal with that, both psychologically and emotionally. (P4)

### *It is like you are living someone else's life*

Some caregivers talked about how their role had resulted in a shift in their lifestyle. They felt overwhelmed. Caregiving occurred among other numerous family responsibilities, impacting the ability to focus on their own lives. As a result of the demanding role, caregivers were isolated with limited interaction outside of the home environment.

It has also affected my life, in a way that my life is just shuttered because I can't go anywhere, I cannot even look for a job because I am worried about mum, so my mind is just there.... mhhhh. (P3)

The biggest challenge is (silence....) is eeeh, time, the time you put in taking care of that person. You cannot work, you can't do anything else, you are just there, it is like you are living someone else's life. (P1)

For some caregivers, the demands for caring seemed overwhelming, making it difficult to balance competing responsibilities:

I normally get up at 4 am so that I can prepare breakfast and lunch for my husband, and also, I live with a grandchild who was abandoned here by my daughter. So I have to prepare her for school as well. I also have a cow that I milk, and that also needs to be fed. Once that is done, I then go in search of some casual work. (P6)

If I cannot find someone to look after her, I cannot leave this house. I cannot go to church or the market. If I am to go anywhere, I have to pay someone to mind her for a few hours while I rush to church or the market. (P10)

Only in a minority of instances, the role did not have the same impact on caregivers, particularly when the person living with dementia was more independent:

He is quite independent and does not rely on us to do much for him, and he takes a walk every day with the caregiver, they can walk as far as XXX. (P10)

### *Caregiving is a rewarding experience*

Despite these struggles, caregivers related some positives aspects. The role had provided some with new insights into themselves and their situation. Some had become more patient, understanding and gained knowledge:

Yes, there is a positive aspect (the person living with dementia mumbles). Even if this experience has hurt me so much, it has affected me so much. It also changed me in a way. I am very patient nowadays, in the beginning, I used to cry as I washed him, but these days I can even sing... you know. (P1)

Another caregiver talked of having found meaning in their feeling of self-worth. The experience had made them knowledgeable, and they felt confident sharing and educating others:

The experience has made me more understanding of others. If it didn't happen to me, I would not understand it in the same way. I have the information and can help other people, and I am usually not scared of talking about it. For me, the positive thing is being able to educate others. (P4)

### **Supports to assist with caregiving**

This theme examines the supports caregivers had available to them and centred around the experiences with receiving support from family and paid caregivers. Four caregivers provided care on their own and received sporadic family support, while six employed caregivers to provide hands-on care. The majority of caregivers felt that close family members were not involved or even concerned about the person living with dementia.

#### *They have to take care of us*

Most caregivers talked about the financial burden associated with caregiving. Financial support came mainly from close family members. Some got a respite from friends, which enabled them to attend support groups or social events. Some caregivers were managing well, with close family members, particularly their children, providing financial support:

In terms of food, we are ok; there is no problem with food here. We get support from the children; they are the ones who buy food for us. (P9)

The children have been very supportive with talking to me and encouraging me, and I thank God for them. I do not take this for granted because I know many children who do not support their parents even under normal circumstances. (P10)

[] Even if you have children who help you, they have their own lives, so if there is a way of providing families with such a person with financial support, this would help. (P2)

For some caregivers, there was no family support, and they struggled on their own both financially and with hands-on care:

[]Yes, just me. I have sisters, and none of them helps me. They do not even visit us (the person living with dementia says ‘they never come’). I usually ask them to send me at least a little money. They don’t seem to care. They always say they will come, but they never show up, never, and I am telling the truth. (P7)

### *I have employed someone to take care of him*

Families employing a caregiver tended to be those in which the person living with dementia was a parent or a male spouse. The paid caregiver provided hands-on care while a family member (a daughter or spouse) took care of the day to day running of the care. Paid caregivers had no formal training and charged less compared to trained caregivers.

I cannot say that I am the primary caregiver because I do not live with him. I have employed someone to take care of him. So he lives in XXX, and I live around here. But I basically handle a lot of stuff, his medication and his general welfare. I am the one who is mostly in charge. (P4)

Some families found it challenging involving paid caregivers as the care they provided was perceived as poor. But, because it was difficult to find people willing to be employed, families had to persevere:

[]ohh, that is now another thing because, for them, they are there for work, and at times you feel that whatever you are telling them does not really bother them, sometimes you remind them to give medication, and they tell you they forgot. When you ask them, you see they are not happy, [] it is not easy, again you do not want to show them that they do not know their work because once they leave, getting someone who can provide care is not easy. So you find that, as much as you want to complain, you calm down. (P3)

## **The perceived unmet care needs**

Participants talked of a range of unmet needs. These included (i) the lack of diagnosis and/or misdiagnosis, (ii) lack of knowledge on dementia and dementia care skills and (iii) limited emotional or practical support, including respite care.

### *Lack of diagnosis and/or misdiagnosis*

*The biggest challenge is, first of all, diagnosis.* The need for supports with the diagnosis was a dominant theme across all interviews. Challenges to accessing diagnosis services were cited as cost, lack of services for people living with dementia, lack of knowledge about dementia among healthcare



professionals and the belief that the condition is a normal part of ageing. The government's need to be involved in dementia care and train healthcare professionals was articulated in all interviews.

They need to have a dementia policy for the country, and I also hope that they can come up with a one-stop-shop where people with dementia can access all the services they need. And I am looking at this from diagnosis, medication, you name it, [ ], but it also calls for the government to train the healthcare professionals and to include modules on ageing and dementia in the medical and nursing schools. (P4)

The costs, coupled with a lack of understanding of the condition, prevented families from seeking formal diagnosis:

The money, there is a time we were told we need 60,000 ksh. We were being told that this doctor would prescribe medication that would cure her condition. I was just being told by another lady friend of mine. (P7)

For those who had a definitive diagnosis, it had taken long to get one:

So there is a doctor in our town here who recommended that he goes for a memory check-up. So he went, and the diagnosis was made, but he had the condition for quite a long time before eventually going to a specialist. The diagnosis was dementia. (P5)

### *Lack of knowledge of dementia and dementia care skills*

I learnt that my spouse had Alzheimer's in the support group.

The lack of public awareness and understanding of dementia was a notable theme, and this translated into a lack of knowledge and skills among people when they must become caregivers. This knowledge gap made it difficult for caregivers to convince family members that what their loved one was experiencing was a result of an illness:

Yes, I have talked to people about it, but let me tell you, it is not easy for people who have not experienced this to understand. People do not understand what dementia, what Alzheimer's is. You try to explain to people they tell you aahhhh I do not think she is sick, I think she is just old, you know. (P3)

Four out of the 10 caregivers interviewed had access to a support group and talked of the benefits of such a group, particularly at the disease's initial stages. For the other 6, there was no support group in their locality, and they had not made efforts to reach out to other families in the same situation.

So the situation with my husband continued for a long time, and this stressed me a great deal because I did not understand what was going on, and at that time, there was no support group like we have now. If I had been part of a group, I would have understood what was going on with my husband. (P2)

When faced with few alternatives and a lack of support, caregivers talked of using their own knowledge and try and error techniques to manage caregiving. Most caregivers, therefore, learnt on the job, and for families employing caregivers, it meant training them with limited knowledge. This no doubt had implications for the quality of care that the person living with dementia received:

But usually, caregivers stay quiet, trying to manage the situation on their own, and no one else knows what they are going through. [ ]You are in the dark with no information on how to manage this situation. One is continuously trying to devise new ways and techniques to cope in order to provide care. (P5)

We cannot afford trained carers, so we use untrained ones and train them ourselves, and one of the things we instil in them is that the condition of the person they will be caring for will not get better. Sometimes they might ask me a question in relation to a behaviour of XXX or a condition that I have never experienced before. I have to be honest with them often and say that I do not know how to deal with it. (P3)

Caregivers underscored the need for training in practical caregiver skills. Some caregivers acknowledged the importance of understanding how dementia impacts the person, which would help them manage potential communication and behaviour problems that make caregiving difficult. The need for a national dementia care training programme was articulated in most interviews:

[ ] There is a need to provide training for caregivers. If I think of my own situation, I made a lot of misses at the start, wondering how this person should be handled. So I just provided care as best I could. You know this person is in their own world, and it requires as a caregiver you go into his world. But as a caregiver, if you remain in your world and then wonder why this person cannot reason, you probably do not realise that he can't, so I would say that training is very important. (P2)

Also, training both male and female caregivers, but also that they make their services affordable because hiring a nurse per shift is very expensive. It is important they train caregivers to provide person-centred care. This would provide us with a pool of caregivers who can be called upon at any time to provide relief services. (P4)

One caregiver talked of the need for caregivers to be proactive in finding out information on their own about dementia and caring for a person living with dementia:

I encourage caregivers to do as much as possible to get more information about dementia. (P4)

### *Lack of emotional or practical support for caregivers*

I am here with my struggles, and at times this situation makes one start think a lot.

Some talked of their isolation and the potential benefits of being involved in support groups. They stated the need for caregivers to meet often and share experiences:

[ ]But it is very difficult to even know other caregivers around here, so I am here with my struggles, and at times, this situation makes one start think a lot [ ]. For me, the way I see it, people who care for these people would need to meet and share their ideas and open up about issues we face and how we can manage. (P5)

[ ] also having a meeting or workshop to meet other people who are caring for such a person so that other people can give you encouragement, and then you realise you are not alone. (P10)

Respite care was particularly lacking, making it impossible for caregivers to take a break from their duties. The lack of respite presented physical and emotional problems for this particular caregiver:

No one else assists me. If I would need to go somewhere for a day, the option would be to employ someone to look after him while I am away. But most people would not accept to do this kind of job, so I just do this work on my own. Even family members, no one would help me. (P6)

And in the case of families that had employed a paid caregiver, one participant maintained:

Another difficulty is when the paid caregiver goes on leave, and I have to get a temporary replacement during that period. That is really stressful because getting a male caregiver has not been easy; you will look and look and look and get one, then you realise, eh, this one just came here for the money and not for the job. (P4)

Several participants echoed the lack of government involvement and support for people living with dementia and their families. One paid caregiver talked of the lack of protective equipment that would ensure the health and safety of caregivers when providing personal care:

In my experience, if the government wanted to help us as caregivers, they would empower us more by supplementing our income so that we are able to do this work well and support our own families.[] They should give us personal protective equipment, pads and clothes for these people. We need equipment like the ones used in hospitals, we have gloves, but we also need additional protection from the smells and potential infection. (P9)

## Discussion

This article reports on the lived experience of caregivers for people with dementia in Kenya. Using a phenomenological approach, we identified three major themes from the data. These were linked to how caregivers experienced and managed their role, the impact of caregiving on their daily lives and which perceived unmet care needs existed.

Caregivers emphasised the emotional struggles. All caregivers described their experience as stressful. The disease's initial stages were described as the most difficult and challenging behaviours of the person living with dementia made caregiving difficult. Caregiver grief, defined as 'the caregiver's emotional, cognitive, and behavioural reactions to the recognition of personally significant loss' (Meuser et al., 2004, p. 175), emerged as a major stressor based on caregivers' accounts. Trying to manage this ongoing experience of grief alongside a loved one's challenging behaviours took a significant psychological and physical toll on participants. Most talked of being sleep deprived, being engaged with caregiving duties almost 24 hours a day and consequently having no time to look after their health. Most perceived their health as poor and felt that continuing their caregiving role would eventually lead to a further decline in their health. The importance of supporting caregivers to enable them effectively care for themselves while maintaining their role is a constant theme in the caregiver literature (Brodaty & Donkin, 2009; Sullivan & Miller, 2015). There is a pressing need to develop flexible interventions tailored to individual caregivers' needs to improve caregiver well-being. There is emerging evidence of the potential for technologies, for example, mobile phones, to support the delivery of caregiver interventions (Eisdorfer et al., 2003), but further research co-designed with caregivers is needed to ensure acceptability and uptake of such interventions, as well as suitability to the local context.

Despite the stressful nature of the role, participants also reflected on positive aspects. Some talked of finding growth and of self-development brought as a result of gaining new insights about themselves and knowledge about dementia. Some had become more patient, understanding and even

more loving towards the person they were caring for. Participants said they had increased empathy and a deep understanding that what the person was dealing with was beyond their control. Positive experiences associated with caring for people living with dementia may help relieve some of the stressors that come with this role (Hilgeman et al., 2007). There is a need to develop context-specific interventions that would help caregivers identify those positive aspects to promote resilience in their role.

The second theme described the considerable financial burden associated with caregiving in the Kenyan context. Leaving employment to become a full-time caregiver means loss of income, impacting career development (Mayston et al., 2014). A recurrent theme in all interviews was a lack of financial support or any form of support from the government, a finding consistent with reports in the literature (Guerchet et al., 2017). This is hardly surprising given that dementia is yet to be prioritised in national health policies. As formal support was absent, caregivers turned to immediate family members as the only available (potential) source of financial support. Employing caregiving assistance was not an option for many or was only a short-term option in certain circumstances.

The third theme reflected the lack of knowledge regarding dementia in the wider community and unmet care needs. Having limited knowledge, inadequate information and limited professional advice exacerbated the challenge of caregiving. The belief that dementia resulted from the normal ageing process meant some families did not think it appropriate to seek professional help. This is a consistent finding in SSA studies (Agyeman et al., 2019; Mushi et al., 2014). It would appear that because of the way dementia is understood and conceptualised in this context, there was a stigma attached to having a family member with dementia. There is a need to develop educational interventions and peer support at the early stages of the disease for caregivers. These can be channelled through existing caregiver support groups which were deemed hugely instrumental in this study to those who had access to them.

Early diagnosis and intervention are important for families to understand the memory and behavioural changes of the person living with dementia. This may help families access practical information and plan (Martin et al., 2011). In the current study, caregivers talked of misdiagnosis on multiple occasions or receiving incorrect information from a health professional. Most talked about being prescribed medication that was not effective in alleviating dementia symptoms. This is closely linked to the perceived lack of dementia knowledge and skills to recognise and make the correct diagnosis among the healthcare workforce. This is a common theme in studies conducted in SSA (Mahomed & Pretorius, 2020). The need for awareness-raising about dementia and the development of national dementia strategies is reiterated in the WHO's global action plan on the public health response to dementia (WHO, 2017).

In particular, some caregivers, caring for a spouse, viewed caregiving as their duty and sole responsibility. This can be explained by the fact that dementia in this context is viewed as a normal part of ageing and that families would get by without asking for hands-on support or sharing their emotional experience. This finding contradicts others in the literature (Quinn et al., 2008) where caregivers shared their family members' struggles. In our study, caregivers with access to support groups talked of sharing their feelings openly at meetings. It was apparent that those linked to support groups received emotional support, practical advice and helpful links to professional services. Caregivers with no support group expressed a desire to be part of such a group. Support groups form a crucial part of family caregivers' support and can act as champions for people living with dementia and for their caregivers (Brodsky & Donkin, 2009). Support groups are key to promoting resilience in caregiving and reducing feelings of isolation. This low-cost, readily actionable intervention should form part of efforts to address dementia and dementia care at a national level.

### *Limitations and future research*

This study has a few limitations: First, the study used a small sample size and was conducted in 3 out of 47 counties in Kenya, although the sample is in keeping with the IPA approach. While the results may not represent the range of diverse views of caregivers for people living with dementia in Kenya, the study provides valuable insights into a topic that has not been sufficiently studied in this context. Future research on the topic should include the views and experiences of caregivers from multiple counties in the country and explore how support and knowledge may vary. This insight would support the effective targeting of interventions to enhance knowledge, encourage help-seeking and reduce the stigma associated with dementia.

Second, our sample consisted mainly of female caregivers. The gender imbalance in our study is striking in terms of caregiving being seen as a female role. The difficulty in accessing male caregivers likely speaks to men's underrepresentation in caregiving roles. As such, it is not a limitation of this study specifically but is a reflection of the socio-cultural realities. Further research should seek to include the perspectives and views of male caregivers.

Despite these limitations, our study contributes important findings and insights into the realities of caring for people living with dementia. Our study can inform the formation of support programmes, the creation of public health awareness initiatives and the development and implementation of a national dementia plan for the country, including training programmes for caregivers and healthcare professionals.

### **Conclusion**

This study explored the experiences of caring for people living with dementia in Kenya. Consistent with other studies, we found that caregiving was associated with emotional, financial and practical challenges. Our study highlighted a general lack of knowledge and awareness of dementia among families, healthcare professionals and the general public, with dementia often considered a normal part of ageing. This no doubt calls for training and educational programmes and awareness-raising initiatives for the public. There is a need for research to examine how to communicate best and achieve the intended impacts on the family, healthcare settings and the general public.

### **Acknowledgements**

We appreciate the caregivers who participated in this study and the local organisations involved in the recruitment process. We thank Dr Naomi Mutea and Dr Mary Joy Kaimuri (School of Nursing, Meru University of Science and Technology-MUST), who offered support with local ethical approval and research permit processes.

### **Declaration of conflicting interests**

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

### **Ethical approval**

Two ethics review committees granted ethical approval: Kenya Methodist University (KeMU) (reference: KeMU/SERC/EXT/64/2019) and University College Dublin (reference: LS-19-55-Mwendwa). Subsequently, a research permit was obtained from NACOSTI (reference: NACOSTI/P/19/1095).

## Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

## ORCID iD

Purity Mwendwa  <https://orcid.org/0000-0003-3774-468X>

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**Purity Mwendwa** is a global health researcher and currently a post-doctoral research fellow in the UCD Centre for Interdisciplinary Research, Education and Innovation in Health Systems (**UCD IRIS**), School of Nursing, Midwifery and Health Systems, University College Dublin, Ireland. She has extensive experience with qualitative and participatory research in Africa and Ireland. Her previous and current research involves doing research in disadvantaged communities to understand barriers they face in the access to resources, services and opportunities. She is currently engaged in research that targets older populations, in particular those with dementia and related neurocognitive conditions in the African continent and among immigrant populations in Europe.

**Elizabeth Mutunga** is a trained psychotherapist and HR practitioner and an Alzheimer's soldier. She is the CEO and Founder of the Alzheimer's and Dementia Organization Kenya (ADOK). Elizabeth developed interest in Alzheimer's disease after her father was diagnosed in 2007. At the time, the disease was a mystery to her and her family. Therefore, in trying to understand how best to cope with the disease and care for the father better, she started looking for a support group where she could plug in and get support, encouragement and walk with other caregivers. The passion to continue helping other caregivers cope with the care of their loved ones was born in this journey, and it led her to start a support group that could reach out to more people after her father succumbed to the disease 2009. The support group has been running since 2013 once a month. She is passionate about ensuring that families and their loved ones who have dementia understand the disease. Through ADOK, she uses the platform to ensure that awareness is created about dementia and Alzheimer's disease and stigma associated with Alzheimer's is reduced and Kenya has Alzheimer's/dementia-friendly communities.



**Thilo Kroll** is Professor of Health Systems Management University College Dublin (UCD), School of Nursing, Midwifery and Health Systems, Ireland. His research interests are on the social dimensions of health and well-being with a particular emphasis on public health perspectives on disability and health topics. He has led a variety of interdisciplinary research studies combining quantitative and qualitative research methods with a particular emphasis on inclusive research designs for otherwise marginalised groups.

**Aoife De Brún** is an Assistant Professor/Ad Astra Fellow at the UCD Centre for Research, Education and Innovation in Health Systems (UCD IRIS) at the School of Nursing, Midwifery and Health Systems in University College Dublin. She is a registered chartered psychologist with the British Psychological Society with experience of multi-disciplinary projects in health research. Her research interests include a range of topics in applied health and organisational psychology including team dynamics, collective leadership, medical decision-making and patient and public engagement in research.