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# A qualitative investigation of the psychosocial services utilised by care-givers of patients with Alzheimer's disease and related dementias in southwestern Uganda

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## Abstract

Individuals with Alzheimer's disease and related dementias often require substantial support from other people. Much of the care-giving is from family members who eventually experience physical, emotional and financial stress, depression and fatigue. In Uganda, families are a cornerstone in providing care to individuals with dementia. However, little is known about the psychosocial supports available to the care-givers in their care-giving role. We assessed the psychosocial supports available to care-givers of individuals with Alzheimer's disease and related dementias in southwestern Uganda. We conducted 34 in-depth interviews at three referral hospitals at which care-givers identified by the treating clinicians were approached for informed consent. The interviews were conducted until thematic saturation was reached, and the interviews were translated and transcribed. Thematic content analysis was used to analyse the data. Care-giver supports were structured into two major themes: medical supports utilised and supports beyond the medical care system. Medical supports highlighted information provided by medical professionals. Supports beyond the medical care system included emotional and instrumental supports provided by religious leaders, the local communities and family members. Care-givers for individuals with dementia in southwestern Uganda receive educational support from medical practitioners, and unstructured emotional and instrumental supports from the family and community.

**Keywords:** Alzheimer's disease; dementia; low- and middle-income countries (LMICs); psychosocial support; care-giver

## Introduction

Dementia is a clinical syndrome characterised by neurodegeneration that causes irreversible decline in cognitive functioning. The most common cause of dementia is Alzheimer's disease (Alzheimer's Disease International (ADI), 2018). About 50 million people worldwide were diagnosed with dementia and these numbers are expected to increase by 281 per cent by 2050 and over 60 per cent of them reside in low- and middle-income countries (LMICs) (Prince *et al.*, 2013; Mubangizi *et al.*, 2020). In sub-Saharan Africa, 2.13 million people experience dementia, including 4.5 per cent of individuals over the age of 60 in east sub-Saharan Africa (ADI, 2017). As this prevalence is expected to rise by 65.7 million by 2030, this rapid growth in prevalence will place higher demands on dementia care in this region (Prince *et al.*, 2013).

Individuals with dementias experience impairments in memory, communication, attention, reasoning, judgement and visual perception, as well as changes in mood and personality, that limit their ability to function independently (Malhotra, 2018). The behavioural and neuropsychiatric problems associated with dementia (*e.g.* anger, worry, wandering and delusions) in combination with the affected individual's daily care needs (feeding, dressing, bathing) place a high burden on informal care-givers, such as family members, friends and paid in-home assistants (Schneider *et al.*, 1999; Chiao *et al.*, 2015; Cheng, 2017). Accordingly, these care-givers experience high levels of chronic stress and depressive and anxiety disorders, which can in turn exacerbate the behavioural and psychological symptoms of dementia (Schulz *et al.*, 1995; Schulz and Martire, 2004; Kales *et al.*, 2015; Allen *et al.*, 2017). Previous studies have proposed that the challenging behaviours observed when taking care of individuals suffering from dementia could be expressions of individuals' unmet needs (Verity, 2008; Heerema, 2020). Although individuals with dementia struggle with their unmet needs, their symptoms are also challenging to their care-givers. Therefore, the implementation of effective care-giver support interventions is central to reducing care-giver burden and behavioural symptoms among individuals with dementia.

To date, the vast majority of research on care-giver burden in dementia has been conducted in high-income countries. An emerging body of research from LMICs suggests that informal care-givers in LMICs also experience emotional distress associated with managing their loved one's daily care routines and challenging behavioural symptoms (Acosta *et al.*, 2008; Liu *et al.*, 2009; Sinha *et al.*, 2017). Care-giver burden and associated distress in LMICs is also compounded by lack of social support and shortage of formal specialised medical care for people with dementia (Schneider *et al.*, 1999; Wang *et al.*, 2014; Ae-Ngibise *et al.*, 2015; Raggi *et al.*, 2015; Ayalew *et al.*, 2019). Given the projected rapid increase in dementia prevalence in sub-Saharan Africa, enhancing supports for care-givers of persons with dementia in this region is of urgent importance.

In high-income countries, interventions for care-givers of people with dementia that target enhancing care-givers' knowledge about the condition and skills for managing challenging behavioural symptoms have been shown to reduce care-giver depression and improve neuropsychiatric symptoms (Selwood *et al.*, 2007; Brodaty and Arasaratnam, 2012). Similarly interventions targeting care-giver dementia knowledge and behaviour management skills have been shown to reduce care-giver burden and distress in India and Russia (Dias *et al.*, 2008; Gavrilova *et al.*, 2009).

However, there is a paucity of data on care-giver interventions in sub-Saharan Africa. A recent review of qualitative studies from sub-Saharan Africa, including studies from South Africa, Tanzania, Nigeria, Ghana and Congo, revealed that care-giving for people with dementia is a collective responsibility among family members and that families often utilised biomedical and non-biomedical treatment approaches such as traditional healers (Roberto and Blieszner, 2015; Anderson *et al.*, 2019). Care-givers also described a desire for further education on dementia from the treating medical providers, and expressed need for greater emotional and financial support to meet their family member's needs (ADI, 2017).

To date, there are no data available on dementia care-giver support interventions in Uganda. Given the limited availability of specialty mental health care in Uganda, it is essential to investigate what formal and informal supports are currently being utilised by care-givers of people with dementia in Uganda. Understanding the support interventions currently utilised will inform the adaptation and integration of evidence-based care-giver support interventions in dementia care in this setting. Therefore, this study aimed to characterise the formal and informal supports utilised by care-givers of individuals with dementia in southwestern Uganda, including by whom the support is provided and the content of the formal and informal support provided.

## Methods

### Study population

Participants were eligible if they: (a) were caring for someone with a diagnosis of dementia aged 60 years and above, (b) had taken care of the person for more than six months, (c) self-identified as the primary care-giver, (d) were a family member or friend of the individual, and (e) were 18 years and above. Care-givers of individuals with HIV-related dementia were excluded because the focus of the study was care-givers of individuals with Alzheimer's disease and related dementias. Written informed consent was obtained from each participant. Participants who could not read and write documented their consent with a thumbprint in the presence of a witness. The interviews with care-givers were conducted at a private location, often in their homes, and at a time convenient for the care-giver.

### Study design and sampling procedure

This was a cross-sectional qualitative study in which we conducted 34 in-depth interviews among care-givers of individuals with Alzheimer's disease and related dementias at three referral/teaching hospitals in southwestern Uganda: Mbarara and Kabale Regional Referral Hospitals (MRRH and KRRH), and Kampala International Teaching Hospital (KIUTH). The three hospitals offer specialised psychiatric services to a catchment of about 8,874,862 people, 14 per cent of whom are over 60 years of age (Uganda Bureau of Statistics, 2014). Although care-giver support for dementia is delivered locally within parish-based health centres, participants were recruited from the regional referral hospitals to leverage the diagnostic expertise of psychiatric staff at the referral hospitals for the identification of dementia.

Care-givers of people with dementia were purposively sampled from the outpatient psychiatry clinics of MRRH, KRRH and KIUTH. Due to methodological limitations, a clinical diagnosis of Alzheimer's disease is not made at these sites.

Individuals are instead diagnosed with dementia, which is classified as HIV-related or non-HIV-related. Non-HIV-related dementia is considered to be possible dementia. The care-givers of the individuals diagnosed with dementia were identified by the treating clinician and then approached by study staff who introduced the study and explained the study purpose and objectives. Upon expressing interest in the study, study staff scheduled an appointment to obtain informed consent and complete the interview at the convenience of the care-giver.

### **Interview guide for qualitative interviews with care-givers**

An in-depth interview guide was developed to explore the dementia care-giver support available in rural southwestern Uganda, including the type of services utilised by care-givers and by whom the services are provided. The questions included: (a) what kind of counselling services are available for you as a care-giver of an individual with Alzheimer's disease in southwestern Uganda?; (b) Who usually gives the counselling? What is done during counselling? What do you think of these activities?; (c) What kind of information is provided during counselling; (d) What other sources of counselling services are available for you as a care-giver of an individual with Alzheimer's disease in southwestern Uganda?; and (e) What resources at family and community level do you access that help you to care for the individuals with dementia?

### **Data collection procedures**

The in-depth interview guides were translated into Runyankore–Rukiga, the local language, and back-translated into English to ensure that the message was correctly translated. The interview guides were first piloted with four care-givers of individuals with dementia at MRRH and iteratively revised. In-depth interviews were then conducted in Runyankore–Rukiga by the lead author and two trained research assistants between December 2018 and January 2019. Interviews lasted between 30 and 75 minutes and were audio recorded. In-depth interviews were conducted until thematic saturation was reached.

### **Data analysis**

In the in-depth interviews were translated from Runyankore–Rukiga into English and transcribed by the research assistants, and checked by the lead author (CA) against the audio recordings for correctness of information. Thematic content analysis was used to analyse the data (Braun and Clarke, 2006). CA reviewed transcripts and audio recordings, and developed a codebook based on emerging themes. CA and Eliaililia S. Okello double-coded 29 per cent of the transcripts, compared their findings, and discussed and harmonised their differences until consistency in coding was achieved. The remaining interview transcripts were coded by CA independently. Data analysis was conducted using the qualitative data analysis software ATLAS.ti version 7 (Muhr, 2013). The research team (CA, GZR and CO) discussed the thematic coding in the codebook, the results of the analysis in ATLAS.ti and came up with the final major themes: medical supports and supports utilised beyond the medical care system. [Table 1](#) shows the codes, sub-codes and themes.

**Table 1.** Original codes, sub-codes and themes

Parent code	Sub-code name	Themes
Supports	Professional counselling	Medical supports: <ul style="list-style-type: none"> <li>• information support</li> <li>• limits of these support services</li> </ul>
	No professional counselling	
	Guidance by religious leaders	
	Guidance by community members	
	Internet-based support	
Professional counselling content	Dementia knowledge	
Informal supports content	Emotional support	Supports utilised beyond the medical care system: <ul style="list-style-type: none"> <li>• Emotional supports</li> <li>• Instrumental supports</li> <li>• Supports provided by religious leaders</li> <li>• Supports provided by local communities</li> <li>• Supports provided by family members</li> </ul>
	Financial support	
	Physical support care	
	Information about dementia	
	No resources	
Challenges faced by families	Physical care	
	Financial needs	
	Time commitment	
	No challenges	

### **Ethical considerations**

Participants were interviewed after obtaining informed consent. Ethical clearance was obtained from the Research Ethics Committee of Mbarara University of Science and Technology and the Uganda National Council of Science and Technology. Permission was obtained from the Hospital Management and Psychiatry Unit heads of the respective hospitals to access their records. Additionally, as participants often requested to be interviewed in their own home, local leaders of communities from which the participants resided were also engaged in a discussion of study procedure and risks/benefits and granted their approval of study procedures prior to data collection. Local leaders in this study were gatekeepers to the study community. Their involvement did not influence who was able to participate since their role was only as gatekeepers. We only informed them of our study activities in their community for security reasons. Once a participant was identified, and after ascertaining that they met our inclusion criteria, we requested them to let us know of a place that would be convenient to them for the engagement. We took them through the informant consent process and ensured their privacy was respected. Participants then signed or thumb printed after all the questions were asked and answered to their satisfaction in the presence of the research assistants and the principal investigator.

## Results

### *Participants' demographic characteristics*

A total of 34 interviews were conducted across the three hospitals in southwestern Uganda. Of the care-givers, daughters comprised about one-third (32.4%); most were married (64.7%), and slightly over one-third were aged between 44 and 53

**Table 2.** Characteristics of study participants

Participant characteristics	N	%
Age:		
24–33	12	35.2
44–53	12	35.3
64+	10	29.4
Relationship to the individual with dementia:		
Daughter	11	32.4
Daughter-in-law	7	20.6
Son	7	20.6
Wife	5	14.7
Grandson/niece/friend	4	11.7
Marital status:		
Widowed	2	5.9
Married	22	64.7
Single	7	20.6
Divorced/separated	3	8.8
Education level:		
None	5	14.7
Primary	9	26.5
Secondary	10	29.4
Tertiary	10	29.4
Religion:		
Anglican	21	61.8
Catholic	8	23.5
Islam	3	8.8
Pentecostal	2	5.9
Duration of symptoms of the individual with dementia (years):		
<5	10	29.4
5–10	13	38.2
>10	11	32.4

years (35.3%). Only five care-givers (14.7%) had no formal education, while the majority were of Anglican religious faith (61.8%). Most of the care-givers had been caring for the person with dementia for five years or more (70.6%) (see Table 2).

### **Care-giver support services**

Supports given to care-givers of individuals living with dementia in southwestern Uganda were structured into two major themes: (a) medical support and (b) supports beyond the medical care system. The medical supports highlighted information support provided by medical professionals and the limits of these support services. The supports beyond the medical care system included emotional and instrumental supports provided by religious leaders, local communities and family members.

### **Information support by medical professionals**

Participants reported receiving guidance from health professionals, who were typically the nurses and physicians who provided care to the individual with dementia. Guidance was often focused on symptoms of the condition, possible treatments and explanations about the prognosis. Participants were told of the importance of treating comorbid conditions, several management modalities and referral for specialised management of the different co-morbidities. However, the information given did not include emotional challenges experienced by the care-givers as they cared for their family members with dementia. The care-givers seemed to expect much more than what was provided by the medical professionals. This could be due to the medical model that often focuses on the disease and its treatment, with little or no regard for the psychosocial needs or challenges:

The only 'counselling' I have received is from the doctors in charge of psychiatry about the prognosis of the condition. (49-year-old female care-giver)

Telling me how individuals with dementia behave such as beating people and over reacting ... helped me to take good care of her. (47-year-old male care-giver)

It may thus be useful to incorporate psychosocial and other supports into the traditional medical care. Linking the medical care with reliable community services may be helpful to care-givers for people living with dementia.

### **Limits of medical support**

Most of the participants reported not receiving emotional guidance on how to manage individuals with dementia. They either did not know where to get counselling from or those services were non-existent, as stated by one participant:

I don't get any counselling. I don't even know where they are, because there are no established institutions for me to go for counselling. I am lucky that my wife is a counsellor. She worked with AIDS information centre so when we get time we sit together and talk and we counsel each other ... besides that, I am also a trained

counsellor in my course. I did adult and community education because when we were dealing with old people, we would counsel them so I would counsel them. (65-year-old male care-giver)

The participants highlighted the need for formal counselling supports within the health system to better prepare care-givers on how to manage people with dementia. Participants often noted that they did not know about the condition and in the absence of professional guidance turned to non-professional sources such as guidance from community members, family and the internet:

Well it would be good if there were systems and counselling supports that could prepare caretakers psychologically probably, we don't know much about the condition itself. (47-year-old male care-giver)

In the absence of counselling in the health systems, some participants had to look for self-help resources, *e.g.* on the internet:

I went to internet and googled. So there is that part concerning how the people of Alzheimer's disease are nursed. So I got it from the internet through googling because the doctors had told me that there is no treatment. And on internet I found out that when an individual feeds on coconut oil or put it on bread or food it helps. And I tried it and I got it from internet, so that it could help her. (49-year-old female care-giver)

From this experience, it appears that care-givers go out of their way to look for interventions or supports from health professionals.

### **Support utilised beyond the medical care system**

Participants reported receiving 'emotional support' as well as 'instrumental support' to care for their loved ones from sources outside the medical system, including their religious communities, family and other community members.

### **Emotional support beyond the medical care system**

Participants described receiving support from religious leaders including pastors, sheikhs and priests, and members of their religious community. This support typically took the form of emotional support provided through discussions about personal experiences, prayer, songs and Holy Communion that was noted to improve the subjective mood and wellbeing of individuals and care-givers. The emotional support was in the form of encouragement and advice on how to accept living with people with dementia. This support primarily occurs during social encounters and religious support, as evidenced by the following quotes:

Some people come from church and visit us and we become happy for the whole day, praying and singing and he feels good. And others come to check on [him] and they talk to him ... even community members, family members and other relatives check on us, and when he looks at them, he stops thinking a lot.



(56-year-old female care-giver)

Taking my patient to church to socialise with the rest, and sharing with others helps us to remain active other than being lonely back home. (39-year-old female care-giver)

Going to social places like religious centres seems to be helpful to the care-givers. It is not clear how useful it is to the individuals with dementia.

### ***Instrumental support beyond the medical care system***

The guidance from community members also included instrumental support, such as informational guidance on how to care as well as physical care for a loved one with dementia. However, this support at times contained conflicting advice which was confusing:

You as a person you can look at things whereby one person tells you to go for prayers and another one tells you to see a doctor, then herbalists when you consider what your doctor tells you, you decide on your own which route to follow and sometimes do not know the right or the wrong side to take your individual. (39-year-old female care-giver)

Participants also reported receiving instrumental support in the form of food and money from community members and family. They described that they valued this support highly as they were unable to grow their own gardens due to time spent caring for their loved one with dementia:

Maybe when it's a harvesting season, when a person is coming to check on me, she may bring for me a cup of porridge or beans because sometimes, I can fail to plant anything because of my patient. And I can't even plant a cup of beans or millet. That's the only help we get from the community. (39-year-old female care-giver)

We call family members and talk about where to get medicine like selling her piece of land because medicine is expensive, so we talk about the way forward. She has other children but they are in their homes so when we don't have medicines, they try to get it for her. (33-year-old female care-giver)

Enhancing family cohesion and other supports is feasible and seems helpful.

## **Discussion**

In our study findings, sociodemographic characteristics of care-givers varied by age, gender, religious affiliations, marital status and the relationship to the individuals with dementia. The participants varied (differed) in their demographic characteristics, lived experiences and duration of care-giving for individuals with Alzheimer's disease and related dementias in southwestern Uganda. The participants were mainly female: daughters, wives or daughters-in-law. Care-giving for individuals with dementia in LMICs is most commonly by middle-aged mothers who are married or co-habiting, have completed some or all of primary school, and are self-employed, farmers or unskilled labourers similar to the results of this study (Thrush and Hyder, 2014).

In this study, we found that medical workers often provide diagnostics and prognostic guidance to care-givers but they did not provide sufficient psychosocial support to the care-givers of individuals living with dementia. Many care-givers expressed a need for further guidance on how to care for individuals living with dementia and also how to manage behaviour changes in the persons for whom they cared. Due to the inadequate support from the health-care systems, the care-givers often turn to non-medical sources for information, as well as emotional and instrumental support.

These findings are consistent with previous studies from sub-Saharan Africa which reported that although care-givers are eager to gain more biomedical guidance, support and care for dementia, they often obtain support from outside the formal medical care system, such as religious and traditional healers and community supports (Deist and Greeff, 2017; Hindley *et al.*, 2017; Agyeman *et al.*, 2019). On the other hand, these findings differ from treatment recommendations from high-income countries. In high-income settings, delivery of interventions for dementia care-giver support usually target dementia education, behaviour management strategies, communication skills and care-giver coping skills within the biomedical care system (Selwood *et al.*, 2007; Piersol *et al.*, 2017). This discrepancy is largely due to the difference in available human and other resources.

In our study, care-givers received emotional and instrumental support for their ailing relatives with dementia from sources outside the medical system. These supports were most often obtained from one's religious community, social networks and one's own family. In a similar study in Ghana, care-givers reported facing financial burden, social exclusion, emotional challenges, depression and inadequate time for other social responsibilities. They also reported that the responsibilities around care-giving were mostly shared among close relatives (Ae-Ngibise *et al.*, 2015). This is consistent with cultural values to care for one's family and community. Ideally, members of a lineage are expected to provide each other with instrumental and material resources, and expect to receive emotional, economic and social security. Though families offer a holistic approach to the needs of older people living with dementia, health and social policies offer inadequate scaffolding to support their work (Agyeman *et al.*, 2019). With families becoming smaller, communities and society in general are important sources of emotional and instrumental support for care-givers (Nishio *et al.*, 2017). In a study on unmet needs, care-givers of individuals who were referred to a dementia care programme reported high levels of strain, low confidence in their ability to manage care-giving and access help, and frequently felt that they did not have a health-care professional to help them with dementia-related problems (Jennings *et al.*, 2013). The unique nature and prolonged duration of these needs directly influences the palliative care services and supports required by these family care-givers (Thompson and Roger, 2014). The emotional and instrumental support for care-givers of individuals with Alzheimer's disease and related dementia should entail resources like long-term care insurance, provider care benefits, disability benefits for someone with dementia and social pensions, as well as (a) physical, emotional and psychological needs; (b) information and decisional support needs; and (c) instrumental support needs (World Health Organization, 2015). Previous research indicates that acceptance, optimism, positive communication patterns, family connectedness,

spirituality, social support, economic resources and the effective management of symptoms care (Deist and Greeff, 2017) helps to improve dementia care.

Most care-givers lack knowledge of the supports or they perceive that supports are too expensive. This is because care receivers present too many behavioural and emotional problems (Huang *et al.*, 2009). Care-givers need to know that any unusual behaviour in their ageing family member is caused by the condition, not by 'craziness' or 'meanness', and that they need new ways of responding to the person's cognitive abilities decline (Musisi, 2018). In addition, care-givers need the right information, resources and training. The information needs to include understanding the characteristics and course of the condition, and what resources are available to the families along with training on how to care for people with dementia and how to prevent or deal with the individuals' challenging behaviour (World Health Organization, 2015). Health-care providers need to emphasise to care-givers of individuals with dementia the importance of maintaining their own physical and mental health so that they can continue to provide care for their loved one (Richardson *et al.*, 2013).

Several drawbacks were reported as a result of care-givers receiving support outside the medical systems. Care-givers were told several conflicting messages that varied from individual to individual depending on the experience of whoever visits or shares with them. This is common in situations where there is limited expert information, leaving room for speculations, imaginations and rumours. The individuals who offered this emotional and instrumental support were untrained and only relied on their lived experience or their social and spiritual expertise. The care-givers were faced with many conflicting messages that posed a big problem of which information or message to apply or not as they cared for their ailing family members.

This also runs the risk of misinformation when care-givers take medical advice from community members rather than trained medical professionals. Generally, family care-givers in low-income countries confront barriers in obtaining needed information about behavioural symptom management including but not limited to timely access to information, access to information that is tailored or specific to care-giver's needs, and contexts and usable information that directly informs on how care-givers manage behaviours (Werner *et al.*, 2017).

### **Implications**

Our findings highlight the information and support needs of people with dementia themselves and those of their care-givers. The findings in our study therefore show that there is no psychosocial support given to care-givers of individuals with dementia in southwestern Uganda. The medical system needs enhancement to include an extensive counselling package that is detailed and tailored towards the needs of the care-givers of individuals with dementia. Information about the clinical features, possible risk factors, treatment and prognosis of dementia could help the care-givers to support individuals with dementia. This can be helpful in mobilisation of family and community support systems for the individual with dementia. This information should be provided in simple language that can be understood by the individual with dementia and the care-givers. Information about comorbid disease conditions and their management would also improve the quality of care for

the individuals with dementia. A formal strong family and community social support system should also be encouraged to leverage and learn from the strategies employed by care-givers as part of their lived experiences.

### **Study limitations**

This was a qualitative study which provides in-depth insights into the experience of informal care-givers for individuals with dementia in southwestern Uganda. As care-givers were recruited from hospitals with specialty psychiatry services, the findings of this study may not be generalised to care-givers of individuals without access to these specialty diagnostic services.

### **Conclusions**

Care-givers of individuals with Alzheimer's disease in southwestern Uganda receive unstructured emotional and instrumental supports from the community and family members based on individual experiences. The messages received from different sources are often conflicting, leaving the care-givers in confusion. In such situations, the care-givers attempt all suggested interventions but not consistently. This is usually not good for the individuals living with dementia. The medical care system offers some information about the clinical presentation of Alzheimer's disease but little or no psychosocial support to the care-givers of individuals with the condition. This has implications for how families and care-givers cope with the day-to-day care of individuals with Alzheimer's disease in Uganda and calls for institutionalisation of structured psychosocial support for care-givers to improve the care given to individuals with Alzheimer's disease in low-income countries.

**Data.** The datasets generated and/or analysed during the current study are not publicly available since the same data (transcripts) are being analysed to write another manuscript for other objectives of the same study but are available from the corresponding author on reasonable request.

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**Conflict of interest.** The authors declare no conflicts of interest.

**Ethical standards.** Ethical clearance was obtained from the Research Ethics Committee of Mbarara University of Science and Technology (approval number MUREC 1/7) and the Uganda National Council of Science and Technology (approval number SS4882).

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