

Experience of Caregivers for Older Adults in Rural Ethiopia: Challenges and Available Social Support for Family Caregivers in Co-Residential Living Arrangement

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Abstract

Family and kinship care is a common way of caring for older adults, particularly in rural Ethiopia, where institutional care arrangements are nonexistent. Moreover, the majority of studies on family caregivers of older adults were conducted in western cultures, which makes it difficult to understand family caregivers in the Ethiopian context. This study aims at exploring the experience of family caregivers for older adults in a co-residential setting. Specifically, it focuses on answering caregiving challenges and available social supports for family caregivers in a co-residential living arrangement. This study used a qualitative research method employing phenomenology to understand the lived experience of family caregivers for older adults in rural northwestern Ethiopia. Data were collected through a semi-structured interview with eight purposefully selected family caregivers of rural older adults. Regarding family caregivers's challenges and available social supports, four themes emerged from the collected data. These are economic challenges, the incongruence of older adult needs and caregiving capacity, work-caregiving conflict, work-social life conflict, and the presence of social support from different individuals and community-based institutions. In addition to strengthening caregiver support environments, it's critical to develop the capacity of family caregivers through training, economic support, and the integration of family caregivers with health extension workers.

Keywords

family caregivers, lived experience, qualitative study, rural Ethiopia, older adults

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Background

Despite changes in family size and structure over time, families in sub-Saharan Africa will undoubtedly remain the primary providers of elder care (Adamek et al., 2020). In sub-Saharan Africa, a rapidly aging population is presenting challenges to health care systems (Frost et al., 2015). Caregivers for older adults with high dependence or health problems reported assisting their care-receivers with ADLs like assisting with toilet visits, helping with personal hygiene, assisting with movement, and dressing (Lam et al., 2024). With inadequacies in formal support (Yeandle & Buckner, 2017), eldercare responsibilities have increasingly fallen on the shoulders of informal careers like the family and friends of care-receivers. Literature also shows that family members are the primary source of support and care for older adults with chronic illnesses and disabilities (Schulz et al., 2020).

Among the challenges that older adults experience are vision and mobility problems, loneliness, grief, and sadness; feelings of inferiority in the family; abuse and neglect; a lack of meaningful activities; and the feeling of being a burden on the family (Mefteh, 2022). Moreover, poverty, a lack of trained geriatric professionals, food insecurity, disability and health issues, and long-term care are some of the challenges older adults face in sub-Saharan Africa. Their strengths include indigenous knowledge systems and being holders of cultural heritage, and their contributions to

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development are found to be significant (Adamek et al., 2021).

In sub-Saharan Africa, the lack of government attention to aging issues and the lack of social services targeted to older adults' needs (Adamek et al., 2022) make the role of family caregivers very significant. The costs of formal care and support are already too high and unsustainable, and there is a growing shortage of health care professionals with relevant expertise (Schulz et al., 2020). In addition to using technology-based solutions for older adult care, caregivers are likely to benefit from enhanced knowledge about the disease, the caregiving role, and the resources available to them (Schulz et al., 2020).

Although motives of obligation, altruism, religious values, emotional attachment, economic motive, and reciprocity of care have contributed to co-residential family care (Mefteh & Shenkute, 2022), it's very important to understand caregiver burden with the increasing care dependence of older adults in primary care settings (Chan et al., 2013). Caregivers' subjective well-being was also directly correlated with burden, hours of informal caregiving, and problematic behavior of care-receivers (Verbakel et al., 2018).

Challenges of caregiving include emotional stress (Gray et al., 2016), economic burden and financial struggles and consequences (Gray et al., 2016; Lai, 2012; Nortey et al., 2017; Strommen & Sanders, 2018), and worry due to a lack of knowledge (Gray et al., 2016). Policies and programs to alleviate the financial burden and provide social and financial support for these family caregivers and care receivers are important (Lai, 2012). Family caregiving for older adults with dementia is stressful and negatively affects caregivers' health (Huang et al., 2006). Insufficient access to respite care, difficulty finding and navigating available services and programs, a lack of knowledge and training on care provision, and challenges related to the environmental context of caregiving are common (Strommen & Sanders, 2018).

Family caregivers live a chaotic life, as they have noticed that providing care to an older adult is a difficult responsibility, and they also struggle to balance their caregiver role with work and social life (Mthembu et al., 2016). Moreover, informal caring relationships are vulnerable because of the health of the care recipient, the health of caregivers, the pre-existing relationship between caregiver and care recipient, and the availability of formal and informal services (McGarry & Arthur, 2001). Comparatively, rural caregivers are more negatively affected by caregiving than their urban counterparts in relation to feeling trapped by the caregiving role, being too demanding, and being a source of difficulty in relationships with family members and friends (Bien et al., 2007).

The vast majority of working-age caregivers are employed and work full-time. Many experience conflicting demands between paid work and caregiving and have to miss days at work or reduce their paid work

hours. Those who provide many hours of care and who reside with care recipients are more likely to quit their jobs, and they may even be fired. As such, they are at greater risk of experiencing poor social, economic, physical, and mental health outcomes (Fast, 2015).

Psychosocial factors such as perceived caregiving competence and social support influenced caregiver burden among older adults with frailty and multi-morbidity (Chan et al., 2013). The financial costs associated with family caregiving were a significant factor in caregiving burden, both for male and female caregivers (Lai, 2012). Regarding caregiving capacity, caregivers enroll their family members in services or attend programs that may enhance their ability to provide care. Moreover, many do not identify themselves as caregivers or lack a caregiving alternative that would allow them to attend educational, support, or intervention programs (Roberto & Jarrott, 2008).

Compared to caregivers who are not stressed, caregivers who were distressed received less social support, were in poor physical health, and experienced more caregiving role strain (Dilworth-Anderson et al., 1999). Age and the attitude of older adults, financial challenges, changing contemporary society, and caregiving stress due to the care recipient's health status influence caregiving (Ene et al., 2022). It's also found that community educational programs are a common, low-cost means of providing information to spouses and adult children faced with the challenges of providing care for aging relatives. Programs typically focus on a variety of topics, such as normal aging, chronic illness, behavior management, communication skills, coping and problem-solving skills, living arrangements, and community resources (Roberto & Jarrott, 2008).

To reduce caregiver burden, increasing social support from caregivers' intimate relationships and family physicians is important (Shiba et al., 2016). Caregiver burden, perceived health status of older adults, and social support of caregivers were found to be significant factors influencing the well-being of family caregivers of older adults (Or & Kartal, 2019).

As a way of coping with caregiving challenges, strengthening the capacity of family caregivers through training and economic support to care for older adults is found to be significant (Mefteh & Shenkute, 2022). The caregivers' religiosity was salient to how they viewed and coped with their caregiver role (Vroman & Morency, 2011). Lack of adequate perceived and received social support can be detrimental to caregivers, and it is important to identify those caregivers at risk from inadequate support to develop effective family-based interventions (Chiou et al., 2009).

Social support for caregivers is important to prevent health implications, burden, and biopsychosocial stress and provide favorable conditions for quality of life by allowing greater freedom to develop their daily activities (Anjos et al., 2015). The presence of higher social support helps to prevent the depressive symptoms of

caregivers (Sandoval et al., 2019). Perceived social support mediates the association between resilience and caregiver burden among caregivers of older adults in Singapore. It is crucial for healthcare professionals, particularly those who interact and deliver services to assist caregivers, to promote and identify supportive family and friends' networks that may help to address caregiver burden (Ong et al., 2018).

Ethiopia is the second most populated country in Africa and the 12th most populous country worldwide in 2020, with 102 million people living (WHO, 2022). The number of elderly people would increase from 3.6 million in 2007 to 10.0 million in 2037 (CSA, 2013). Ethiopia, the largest country in East and Southern Africa, has a projected population of 115 million, with 6.1 million people over 60 years old, making it the largest older population in the region (UNFPA, 2022). In a country where there is no formal support system for older adults, this study shows some of the challenges that family caregivers are experiencing and the available support from their surroundings.

According to Central Statistics Agency, a total of 914,989 are above 60 in Amhara region. This study is conducted in *Fogera woreda* which is found in *South Gondar Zone*, Amhara region. The *woreda* (the third level administrative division of Ethiopia—after zones and regional states) contains 34 *kebelles* (the smallest administrative unit in Ethiopia) out of this 29 are rural *kebelles*. According to *Fogera woreda* agriculture office there are a total 206,717 population living in the area (*Fogera Woreda* Agriculture office, 2005). Based on the data of *Fogera Woreda* Women, Children and Social Affairs Office, in 2015, 1,521 older adults are found and among this 631 are women while the remaining are men. This study is conducted in one of the *Kuhar Abo Kebelle*, one of the 34 *kebelles* found in *fogera woreda*. The main objective of this study is to describe the caregiving challenges and social support of family caregivers of older adults in co-residential living arrangements in rural Northwestern Ethiopia.

The specific research questions of this study are:

1. Describe caregiving challenges of rural family caregivers for older adults in a co-residential living arrangements
2. Describe the available social support for rural family caregivers for older adults in co-residential living arrangements

Research Design

The data in this study are derived from interviews with caregivers, and the transcribed interviews were analyzed using qualitative conventional content analysis, where coding categories are derived from the interviewed data (Hsieh & Shannon, 2005). Qualitative content analysis is suitable when one wishes to obtain deeper knowledge and understanding about a phenomenon. Qualitative

content analysis is an empirical scientific method where the focus is the interpretation of texts. It can be used in interviews when interviewees are allowed to express themselves freely, thus enabling the study of individual experiences.

Techniques like bracketing, which is all about separating the researchers' values, understanding, and not allowing the influence of past knowledge to interfere with the experiences of research participants, are employed (Giorgi, 2009; Chan et al., 2013; Nawaz et al., 2017).

Sampling and Participants

With the specific purpose of understanding the experience of family caregivers for older adults in a co-residential setting, only those family caregivers giving care for their parents in co-residential living arrangements were purposefully selected (Kruger & Neumann, 2006). The purpose of selecting family caregivers as participants in this study is to get a deep understanding of caregiving experiences, which is the main focus of this study (Yin, 2016).

The little concern with estimation or representation and the large volume of qualitative data necessitate the need to keep the sample size small in a qualitative study (Ritche et al., 2003) which justifies the smaller number of research participants in this study. This study also employed snowball sampling as a means of recruiting research participants. The initial participant family caregiver was identified by the researcher himself. This caregiver has helped the researcher locate other caregivers in a coresidential living arrangement in the study area. Other family caregivers who were already participants in the study also helped the researchers locate potential participant family caregivers in the study area (Yin, 2016).

The participants of this study are family caregivers who are children of care receivers and were providing care for older adults in rural northwestern Ethiopia during the study time. Based on the objective of this study, the inclusion criteria for family care providers are: (1) primary family caregivers providing care for older adult parents during the study period; (2) family caregivers co-residing with their older adult parents; and (3) family caregivers who are willing and capable for the interview to provide information.

Data Collection

This study used a semi-structured interview. An interview guide was used to interview family caregivers. Ethical approval was obtained from University of Gondar Institutional Review Board (IRB). Informed consent, confidentiality, and the harm and benefit of the study were clearly acknowledged and discussed with participant family caregivers. Participant caregivers were informed that they have the right to refuse participation at any time or to not respond to certain questions. The

Table 1. Transcription and Theme Development.

No.	Transcribed interview data	Sub-themes	Major themes
1.	"Life is not easy these days. It used to be good in the past. People don't complain about food and clothing. My father needs many things like clothing, food and health service. Because of my economic situation, it's difficult to give him what he needs"	Economic challenges of caregiving for older adults	Caregiving challenges
2.	"Usually I don't go to farmland with my husband and children to collect the products because I have to be with my father taking care of him"	Work-caregiving conflict	Caregiving challenges
3.	"There is no infrastructure here. There is no road, electricity and the topography is even difficult for us. You can imagine how difficult it can be for our parents to walk through this hill with ups and downs."	The physical environment	Challenges of caregiving
4.	"When I face some urgent issues, I need to go outside like for funerals or weddings, it's either my relatives or neighbors who take care of my father."	Support from relatives and neighbors	Social support

interviews lasted from 60 to 85 minutes. All the interviews were conducted in Amharic, which is the mother tongue of the participants. With the consent of participant family caregivers, the interviews were audio recorded.

Data Analysis

The major issue before analysis is organizing the data for analysis (Creswell, 2007). The researchers recorded the interview with family caregivers. The interviews were conducted in Amharic, which is the mother tongue of study participants in the study area. Then the researchers translated and transcribed the data at the same time. The data was transcribed word by word. Then, a colleague with language expertise checked the translated data with the raw data. The errors found were corrected before any other process. Thematic analysis was used to make sense of the data and understand what the information communicated. According to Whittaker (2009), thematic analysis has six steps, but the actual analysis involves a back- and- forth movement within these steps.

In order to ensure the accuracy of the data and increase its quality, we have listened to the audio recordings of all participant caregivers. Secondly, one of the researchers who conducted the interview shared the context in which the interviews are made. Finally, we have created a collaborative environment in which we have critically engaged in one another's interpretations (Rodham et al., 2015). Table 1 shows how transcribed data were coded and developed in to sub-themes and major themes.

Findings

Data collected through interviews with eight individual family caregivers for rural older adults was organized and developed into themes. From the data collected through the interview, major themes identified are *economic challenges, incongruence of older adult needs and caregiving capacity, work-caregiving conflict, work- social life conflict, and the presence of*

social support. Table 2 below is the socio-demographic characteristics of participant family caregivers and care receiver older adults.

Economic Challenges

It is difficult for family caregivers to care for their older adult father or mother because of their extremely poor living conditions. Family caregivers (CG7 & CG1) pointed out the financial challenges of caring for older adult parents. This study clearly shows that caring for one's mother and father presents various difficulties for caregivers. In relation to economic challenges, CG1 and CG8 pointed out the difficulty of caring as their economic condition keeps deteriorating.

In the past, we had enough cereals and cows to feed the whole family and relatives. But at this time, since the number of people is increasing, the size of land ownership also decrease that makes difficult to take care of our parents, even our children (CG1)

It's really bad time to not able to take care of our parents. Everything is expensive these days and our parents don't really know how difficult it is to take care of them. My father think life is the like the old days and he even don't know the price of goods. He is living in the past (CG8).

Work-Caregiving Conflict

Some family caregivers also pointed out that their role of caregiving for older adults has caused difficulties to do their daily work routines like farming activities and going to market places to sell and buy goods. CG5 expressed his experience as follows:

Except my husband, I don't have anyone that helps me of farming activities and looking after the cattle. My children are living in town for schooling and they are only here in the weekends. My father needs serious follow-ups because of his health complication. He is 89 years of age and I

Table 2. Socio-Demographic Characteristics of Participant Family Caregivers and Older Adults.

Participant family caregivers	Sex	Age	Education	Marital status	Religion	Care receiver's sex	Care receiver's age
CG1	F	37	4th grade	Married	Orthodox Christian	Male	69
CG2	F	21	10th grade	Married	Orthodox Christian	Male	68
CG3	M	43	Read and write	Married	Orthodox Christian	Male	70
CG4	F	28	Illiterate	Married	Orthodox Christian	Male	67
CG5	F	44	Read and write	Widowed	Orthodox Christian	Female	86
CG6	M	28	Illiterate	Married	Orthodox Christian	Male	70
CG7	F	30	Illiterate	Married	Orthodox Christian	Female	76
CG8	M	36	10th grade	Married	Orthodox Christian	Male	67

cannot leave him by himself and I just let my husband to do farming activities and I stay with my father at home to take care of him.

Caregiving-Social Life Conflict

Different social activities like weddings, funerals and bereavement of family of the deceased, and gathering for religious and cultural holidays are also influenced by the caregiving.

My relatives and friends are not really happy of me missing events like bereavement of family of the deceased and doing some collective religious practices in the neighborhood. I have to be with my mother and take care of her and on the other hand, it's common to stay two to three days in weddings and family of the deceased for bereavement (CG5).

The Physical Environment. The environment in which some of the caregivers and older adults co-reside is very difficult for the aged ones to do some basic activities. Among others, difficulty of accessing age friendly roads to go to institutions like church and health facilities were mentioned during the interview with family caregivers.

Her health condition is deteriorating. She is challenged to move particularly when she wants to move out of home for church. The land scape is very challenging too. Sometimes, when she requires health services, it's difficult for us to take her to health centers. The land scape is challenging and unsuitable even for us who are with good physical condition and health. My every day concern is for her not to fell and die while she is trying to move out of home. (CG 7)

In relation to the physical environment, family care givers stressed the importance of religious attachment for older adults and the challenges of accessing this much needed institution because of difficult landscape for the aged.

In our community, when people get old, it's very common to attend religious practices and develop a strong attachment

with churches, god father and priests. The landscape is full of ups and downs and sometimes, I am expected to take him to church so as to help him pass all the terrain and hills (CG3).

In old age times, institutions like churches and health facilities are very critical for older adults. Particularly, older adults' affiliation to church and religious leaders is very common and inability to access this institution creates a challenging situation for caregivers.

Feeling of 'Not Good Enough'

Some family caregivers think that they are not good enough for care receivers considering what their parents had done when they were a child. A family caregiver (CG5) stressed that she is not paying back what her mother has given her when he raised her.

When I was a child, my mother and father gave me everything they had. I didn't have problem with food, cloth or shelter. Although I did some help like keeping cattle and do house chores, they raised me and cover the expense for my marriage. After my father died, she is now living with us and I feel bad not being able to give her what she deserves to get. Our land is not giving us good yields and we have children to take care and it's very bad to be in the position where I am unable to give my mother what she deserves (CG5).

Lack of Caregiving Knowledge

Family caregivers also lack the necessary knowledge and skill to take care of older adults with health complexities. A caregiver (CG1) said that she don't know how to take care of her father with chronic illness.

I didn't know that my father health condition requires a serious special treatment and he used to eat all food that we used to eat until a health extension worker informed me about the things I should take care with my father (CG1).

Sometimes I get confused of what my father needs. I tried to give him what we have in the house but he always complain about his life as unsatisfactory saying his past life

was good. He says he had a good network with his friends and institutions like church (CG8).

My father is an asthmatic patient. For a very long time, our cattle and we live in a single house and I didn't know that living with cows deteriorate my father's health condition. It's after we took him to a health center and health workers warned us the need to build a separate house for our cows so as to make my father's health condition better (CG3).

Social Support

Support from relatives, presence of local organizations like *mahber* (a religious event of social gathering formed by a group of people who come together to celebrate and feast on the day of a saint or angel they choose monthly) and religion and religious leaders were also considered as social supports lowering family caregivers' caregiving challenges.

My father is happy when there is mahber. There is Mahber once a month and at that time relatives and other community members will come together. Member will prepare the feast for the Mahber members at his/her house. My father talks with his age mates and plays with children (CG5).

Although caregiving for older adults is considered as challenging, the availability of social support from family members, relatives and friends are considered as important mediating factors for those caregiving challenges.

My father is not happy of his current living and health conditions. As a result, he always complains of not getting the appropriate needs and care. He is happy when there is a religious thanksgiving in the house because he gets the chance to talk with other people. He is also relieved when a priest visit our house and pray for his and the health of the whole family (CG8).

Furthermore, participant caregivers considered their older parents' involvement with their friends in different community gatherings as it helps older adults to talk with their friends and stays in other places outside their home.

My father is always interested to go outside and meet some of his old friends and stay with them for some time. This really helps me because after he share some time with his friends, when he come back home, he looks refreshed and happy and that makes me relieved from the feeling that I am not good enough to take care of my father (CG6).

In other ways, family caregivers considered caregiving support from relatives and friends as important. When there is mandatory events to attend, relatives and friends takeover caregiving role of the family so that those family caregivers could attends important social events. In this regard, CG4 elaborated the role of social support as follows:

When there is a funeral that I should attend, a friend in the neighborhood would take care of my father until my return. If there is a wedding that I shouldn't miss, I would just ask one of my relatives to take care of my old father. Sometimes, when there is something that I have to do in town, my relatives covers the caregiving for me during my absence (CG4).

As a way of coping economic challenges, caregiving through rotation is common in a study area. Particularly, older adults with multiple adult offspring are under this kind of caregiving. Some older adults in this study, who do not have the adequate resources to cover for their expenses, are expected live and receive care with multiple family caregivers through rotation.

It's difficult to even feed your own children at this difficult time. So, in order to care for my father, I need my sister to support me in the caregiving. For the last three years, I and my sister have been caring for our father through rotation. After two or three months, he will go to my sister and he will stay with her for the coming one year. When he is away with my sister for care, this rotation care helps me to prepare myself enough to care for my father when it becomes my turn to care (CG1).

Discussion

In this study, consistent with previous studies on factors influencing caregiving (Ene et al., 2022; Gray et al., 2016; Lai, 2012; Nortey et al., 2017; Strommen & Sanders, 2018), economic or financial challenges to care for older adults are stressed. In relation to a lack of knowledge and training in caregiving, family caregivers experience difficulties fulfilling the needs of older adults under their care (Gray et al., 2016; Strommen & Sanders, 2018). With regard to the incongruence of caregiving and social life, family caregivers in this study perceive caregiving as very demanding and its influence on their social life and relationship with their surrounding social environment (Bien et al., 2007; Fast, 2015; Mthembu et al., 2016).

Incongruence between caregiving and work was also found to be a challenge for family caregivers. Although caregivers are expected to do work inside the house and on the farmland, sometimes the conflicting and demanding role of caregiving for older adults puts them in a position to only care for their aged parents at the expense of other basic responsibilities (Fast, 2015; Mthembu et al., 2016). In the study area, it's difficult to easily access services that are very important for the physical and psychological health of older adults. Older adults living in rural areas have reduced access to health care services due to geographical barriers, health care workforce shortages, and limited options for necessary specialty services (Cohen et al., 2021; Jensen et al., 2020), which is similar to the findings of this study.

The inaccessibility of health centers and uncomfortable landscapes to access churches makes caregiving very challenging for family caregivers (Strommen & Sanders, 2018). As a support system for caregiving challenges, caregiving rotation, support from relatives, religious leaders, and the positive role of local organizations are found to be important. Social support is found to be a significant factor in addressing the burden of family caregivers (Anjos et al., 2015; Chiou et al., 2009), caregiving resilience (Ong et al., 2018), and allowing greater freedom to do activities (Anjos et al., 2015).

Implication and Recommendation

Due to the limited resources of the country, the welfare provision of Ethiopia to older adults is minimal in urban areas and almost nonexistent in rural parts of the country. Moreover, the absence of resources to finance long-term care facilities, older adult centers, and a lack of trained professionals (Schulz et al., 2020) in the field of gerontological social workers and nurses makes the contribution of family caregivers very important. Therefore, incorporating capacity building programs for family caregivers in projects like health extension service is important as these caregivers play a significant role in health care burden of Ethiopia (Harvath et al., 2023). It's also important to strengthen social network of family caregivers with their surroundings as supporting caregivers reduce the burden of care and increase a caregiver's well-being (Noohi et al., 2016) which in turn will help family caregivers to not experience work-care giving conflict.

Providing support for family caregivers of rural older adults through caregiving training (Tirrito & Spencer-Amado, 2000), developing small scale older adult centers, making health centers accessible (Mefteh, 2022) will also contribute in addressing the challenges of family caregivers.

Family caregivers' lack of knowledge on how to take care of their aged parents is one of the challenges of caregiving, which can be averted by enhancing the knowledge of caregivers about the disease, the caregiving role, and resources available to them (Schulz et al., 2020). Strengthening the capacity of family caregivers through training and economic support to care for older adults is found to be significant (Mefteh & Shenkute, 2022). Moreover, the integration of family caregiver support programs with health extension workers in rural areas is strongly recommended to fill the knowledge and professional gaps of rural family caregivers for older adults.

Limitation

Any studies are not without limitations. The purpose of this study is only to understand the experience of rural family caregivers for older adults in co-residential living arrangement in the specified study area. It's not intended to make generalization to other family caregivers who are not included in the study area.

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Ethical Approval and Consent to Participate

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