

Understanding the Support Needs and Challenges Faced by Family Caregivers in the Care of Their Older Adults at Home. A Qualitative Study

Gebrezabher Niguse Hailu¹, Muntaha Abdelkader¹, Hailemariam Atsbeha Meles², Tesfay Teklu¹

¹Department of Nursing, Mekelle University, Mekelle, Tigray Region, Ethiopia; ²Department of Health Informatics, School of Public Health, Mekelle University, Mekelle, Tigray Region, Ethiopia

Correspondence: Gebrezabher Niguse Hailu, P.O.Box: 231, Tel +251991235149, Email gerigereking12@gmail.com

Background: As the global population ages, the demand for family caregivers is expected to increase, underscoring the necessity to comprehend their support needs and challenges they face. However, caregiving often comes with various challenges and support needs that require attention. This study was aimed to gain an in-depth understanding of the support needs and challenges faced by family caregivers who provide care to their elderly loved ones at home.

Methods: The study was conducted in Mekelle City, Ethiopia from December 2022 to October 2023 using a phenomenology study design and purposive sampling technique. A total of twenty-two in-depth interviews were conducted using an open-ended guide. The interviews were transcribed verbatim, entered into ATLAS.ti8 software, translated, and analyzed using a thematic analysis.

Results: The study found that family caregivers face communication, financial, medication management, and transportation challenges in caring for elderly relatives at home. It also highlighted several key support needs of family caregivers in the care of elderly relatives at home. These includes financial assistance, training, access to information, and support from healthcare professionals.

Limitations: Qualitative research, by its nature, is subjective as it relies on the perceptions and interpretations of the participants. Moreover, in qualitative studies, researchers typically work with a limited number of participants, in qualitative studies, researchers typically work with a limited number of participants, resulting in conclusions that may not reflect the experiences of all family caregivers.

Conclusion: This qualitative study underscored the multitude of challenges faced by family caregivers in their role as primary caregivers for elderly relatives. The research also highlighted the pressing need for support systems that would address the physical, emotional, financial, and informational needs of these caregivers.

Keywords: family caregivers, older adults, support needs, challenges, home care, qualitative study

Introduction

Family caregiving for older adults at home is a critical aspect of providing care and support for aging populations.¹ As the number of elderly individual increases worldwide, the demand for family caregivers is also rising.² Family caregivers, typically non-professional individuals who provide unpaid care to their older adults, play a significant role in maintaining the well-being and independence of their loved ones.³ However, caregiving often comes with various challenges and support needs that require attention from researchers, policymakers, and healthcare professionals.

Since the war broke out in Tigray in 2020, the lives of the elderly population have been significantly disrupted. One major challenge faced by family caregivers is the cessation of retirement money for their elderly relatives. Without this income, families struggle to meet the basic needs and medical expenses of their older adults, exacerbating financial challenges. Additionally, the conflict has led to a lack of transportation, making it difficult for family caregivers to access essential services or transport their elderly loved ones to medical appointments. Limited access to treatment and medication further compounds the health issues faced by older adults, as the conflict has disrupted the healthcare system and supply chains.

Previous studies conducted have shed light on the support needs and challenges faced by family caregivers in the care of their older adults at home. For instance, previous qualitative study conducted on African American care givers has explored the experiences of African American caregivers and their utilization of supportive services, emphasizing the importance of culturally sensitive interventions.⁴ Another qualitative study examined the role of family caregivers in medication management, revealing the complexity and responsibility associated with this task.⁵

Furthermore, previous study that was focused on the experiences of family caregivers of individuals with dementia and the impact on their social relationships, revealing the strain and isolation experienced by caregivers.⁶ Additionally, a qualitative study on Caregiver burden for informal caregivers of patients with dementia explored the support needs of family caregivers in Asian countries, highlighting the significance of community-based and culturally appropriate interventions.⁷

These studies highlight some of the challenges faced by family caregivers, such as limited access to supportive services, medication management complexities, strain on social relationships, and cultural influences on caregiving experiences. However, despite these valuable contributions, further research is needed to gain a comprehensive understanding of the support needs and challenges faced by family caregivers in caring for their older adults at home. It has also to be noted that, although similar studies have been conducted in developed countries, there is a lack of research specifically focused on the Ethiopian context. Thus, this research aims to fill the gap in existing literature by conducting a qualitative study on the support needs and challenges faced by family caregivers in Ethiopian context when caring for their older adults at home.

Methods

Study Area and Period

The research was conducted in Mekelle, a city situated in the Tigray region of northern Ethiopia. It took place from December 2022 to October 2023. Mekelle city, which serves as the capital and largest city of the region, has a population of around 500,000 residents. It is located at an altitude of 2084 meters (6837 feet) above sea level and is approximately 783 kilometers (487 miles) away from Addis Ababa, the capital of Ethiopia.

Design

Phenomenological Study design was employed to uncover the various factors, emotions, and perceptions that shape caregivers' interactions with their elderly family members and the challenges they encounter and the support needs they need.

Source and Study Populations

Source Population

All individuals residing in Mekelle city, who are 18 years or older and have the responsibility of caring for their elderly family members within their own homes.

Study Population

All selected caregivers within families who were entrusted with the responsibility of taking care of their elderly family members in their own residences.

Sample Size Determination

The number of study participants for the in-depth interview was decided based on the level of saturation. A total of 22 individuals were chosen for this purpose.

Sampling Technique and Procedure

In our study, we employed a purposive sampling method, which is a non-probability approach, to choose participants. Our focus was on individuals who have expertise in caring for elderly individuals in their own households. To identify these individuals, we contacted healthcare professionals like doctors, nurses, and social workers who have regular interactions with older patients. We also utilized community events centered on elderly care and family caregiving to

connect with potential participants. Furthermore, we utilized online platforms, such as social media groups dedicated to family caregiving or elderly care, to expand our reach to a wider audience.

Data Collection Method

With the help of experts, we created a comprehensive English guide and translated it into the local language, Tigrigna. Two skilled research assistants supported us in collecting data by acting as data collection assistants. One assistant used a tape recorder to capture interviews, while the other assistant took written notes. The principal investigator supervised the data collection process. Through in-depth interviews, we gathered detailed information about the experiences, viewpoints, and valuable insights of family caregivers who take care of elderly individuals in their own homes.

Data Quality Assurance

Prior to commencing the actual work, open-ended guiding questions were formulated and discussed with experts. The assistants responsible for data collection underwent training to effectively take notes and record using a tape recorder for a full day. The implementation of open-ended guiding questions was instrumental in preventing any domination from the participants. Following each day of data collection, there was a debriefing session held by both the data collection assistants and the principal investigator (PI). The recorded data were meticulously read, re-read, and transcribed by both researchers and data collection assistants independently in order to ensure the reliability of the data. To minimize any personal biases, the collected data were coded independently by the data collection assistants and the PI. The analysis was conducted by authors who had no involvement in the data collection process. Furthermore, the interviews were conducted in a calm and tranquil environment.

Data Analysis and Presentation

The data collection involved recording information through a tape recorder and taking notes. Afterwards, the recorded data was transcribed and entered into Atlas-ti8 software. It was then translated and coded, leading to the identification of five themes. The thematic analysis method was utilized, and the results were presented in written form and in the form of a table.

Results

A group of twenty-two participants took part in the study (Table 1). The results of the study were summarized in to five thematic areas: Communication challenges and efforts made, financial challenges and efforts made, challenges related to medication management, transportation challenges, opinions on support needs.

Table 1 Socio Demographic Characteristics of Study Participants n(22)

Variables	Category	Frequency
Age	26–44	8
	45–59	14
Gender	Male	8
	Female	14
Marital status	Married	19
	Single	2
	Divorced	1
Kebelle	Ayder	7
	Adishumdhun	4
	05	5
	Adihaki	1
	Adihawsi	2
	17	2
	11	1

Communication Challenges and Efforts Made

The individuals involved in this study have faced a range of obstacles. The most prominent one noted by the participants was a communication challenge. They have described how aging-related changes in behavior, such as agitation, frustration, and verbal outbursts, have made it harder to communicate and comprehend their needs. Additionally, the participants observed that their elderly family members faced difficulties in remembering things and understanding complex information, resulting in confusion and frustration during conversations. The participants emphasized that their older adults found it challenging to express them and grasp what others were saying, which hindered meaningful discussions and meeting their fundamental requirements.

.....One of the biggest challenges I face in caring for my elderly mother at home is dealing with her behavioral changes. As she has gotten older, she has become more agitated and easily frustrated. This often manifests in verbal outbursts, which are difficult to handle. She may snap at me or get angry without any apparent reason. This behavioral change has made communication a real challenge. It's hard to have a conversation with her when she's constantly on edge or exhibiting unpredictable behavior. Trying to understand her needs and desires becomes difficult, as she is often unable to express herself clearly due to her emotional changes....P₂

My father's cognitive decline has been a significant challenge in our caregiving journey. Over time, he has experienced difficulty remembering things and understanding complex information. This impacts our ability to communicate effectively. Simple conversations can turn confusing and frustrating as my father often forgets what we were talking about midway or gets confused with the details. He struggles to find the right words to express himself or comprehend what others are saying. This makes it hard for us to have meaningful discussions or even meet his basic needs.....P₅

However, the individuals involved exhibited great determination and adaptability when dealing with the diverse obstacles they encountered as caregivers for their family members. They implemented tactics specifically designed for their individual circumstances, using straightforward language, exhibiting patience and empathy, and actively attending to their older adults' needs and preferences. These individuals emphasized the significance of employing alternative means of communication, including written messages, text exchanges, nonverbal signals, and gestures, to surmount challenges arising from hearing or speech impairments.

.....Using clear language and active listening helps enormously when communicating with my elderly mother. I make sure to speak slowly and avoid using complex terms. Being patient and understanding are also key. I give my mom the time they need to express her selves, without rushing or interrupting her....P₂

My father has speech difficulties....I have found that other forms of communication are extremely beneficial. We utilize written notes and even nonverbal signals such as pointing or nodding in order to ensure comprehension. Moreover, I have realized the importance of gestures and body language in overcoming communication challenges due to impairments. Basic gestures like thumbs up or thumbs down greatly aid our effective communication.....P₁₃

One participant utilized walkie-talkies and a bell system to overcome the physical distance within their home.

.....As a family caregiver for my elderly mother, who had limited mobility, communication challenges were primarily related to physical distance within our home. It was difficult to hear her from another room or understand her needs when she couldn't come to me. To manage this, we used walkie-talkies and set up a system where she could press a bell or buzzer to alert me whenever she needed assistance....P₁₀

Financial Challenges and Efforts Made

The participants were greatly concerned about the financial difficulties they faced. They emphasized that taking care of an elderly parent at home could be challenging in terms of the financial burden. They mentioned that the costs associated with medications, medical supplies, and healthcare expenses can quickly accumulate, making it hard to balance these expenses with their everyday financial obligations. Furthermore, the caregiver for the elderly expressed that having to take time off or reduce working hours to provide proper care can lead to a decrease in income, adding to the already

strained financial situation. They also pointed out that finding a balance between financial stability and ensuring the well-being of their aging parents is a major challenge that requires careful planning and support.

I struggled with the financial burden of caring for my elderly parent at home. We had to pay for their medications, medical supplies, and healthcare expenses, which added up quickly. It became challenging to manage these costs alongside our own daily expenses....P₈.

.....I found difficult to balance my work responsibilities and the financial costs of caregiving. I had to take time off or reduce my working hours to provide care, leading to a decrease in income. This posed a significant challenge, as I had to juggle between financial stability and ensuring the well-being of my aging parent....P₁.

One person has expressed that he faced financial difficulties as a result of the expenses involved in modifying their home and purchasing assistive devices for their elder.

One major challenge I faced was the unexpected costs of home modifications and assistive devices for my elderly loved one. We had to make our house accessible and safe for them, which involved hiring professionals and purchasing expensive equipment. This financial strain was difficult to handle....P₁₉

Never the less, the individuals involved have utilized various approaches like budgeting, reaching out to community organizations, using their savings, borrowing money from relatives, and exploring government programs and health insurance choices to handle the financial challenges of caregiving.

To manage my financial challenges, I have employed various strategies such as budgeting and prioritizing their needs. I have also sought support from community-based organizations that provide financial assistance to elderly caregivers.....P₁.

..... To manage these challenges, I have utilized my savings and occasionally borrowed funds from supportive family members. I have also explored government schemes and health insurance options to alleviate some of the financial burden...P₁₂

Participants have stated that the termination of retirement funds caused by the war in Tigray in 2020 has had a negative impact. The lack of financial resources has resulted in significant difficulties in providing proper care for their elderly relatives, including the inability to afford necessary medications, specialized treatments, and healthy diets. Despite actively seeking alternative sources of help, like reaching out to local charities and nonprofit organizations, the participants have faced obstacles in obtaining financial assistance and subsidized medical services. The widespread effects of the war have worsened the need for support, making it extremely difficult to find reliable financial aid or sustainable solutions. As a result, the individuals are currently facing challenges in finding effective ways to overcome this financial hardship and ensure the well-being of their older adults.

.....Yes, of course. Before the war broke out in Tigray, my father was receiving money for his retirement. This money was crucial for our family's financial stability and helped cover various expenses, including the care of my elderly grandmother. However, since the devastating war started in 2020, these payments have been abruptly stopped for over two years. As a result, we are now struggling to make ends meet, not only for our basic needs but also for the necessary care and support that my grandmother requires.....P₁₄

.....Certainly, we have been actively searching for financial assistance and exploring various support options. We have reached out to local community organizations, government agencies, and charitable foundations to seek aid for the caregiving and healthcare needs of my grandmother. Unfortunately, the availability of such support is limited, especially in the aftermath of the devastating war. We are constantly struggling to find sustainable solutions amidst this financial hardship.....P₁₆

yes.... Prior to the outbreak of the war in Tigray, my father was receiving retirement benefits, which played a crucial role in supporting our family, especially in taking care of my elderly father. However, since the devastating conflict started, these financial resources have been disrupted for more than two years, leaving us with no means to ensure the proper care, medical expenses, and overall well-being of my grandmother..... we have actively sought alternative sources of support and assistance to alleviate our financial burden. We have reached out to local community groups, humanitarian organizations, and governmental agencies to seek aid. However, given the widespread impact of the war and the ensuing financial crisis, it has been

immensely challenging to secure any substantial assistance. We are currently struggling to find a viable solution to overcome this financial hardship and ensure proper care for my grandmother....P₁₉

Challenges Related to Medication Management

The participants in the study identified challenges associated with managing their medications. To tackle these problems, they took various steps including making charts, using reminders, trying different medication formats, seeking advice from healthcare professionals and pharmacists, and arranging their medicines in portable cases for easy use and safe storage.

One of the main challenges I faced was remembering the strict dosage schedules for different medications my elderly loved one required. To manage this, I created a daily medication chart and set multiple reminders on my phone. Additionally, I sought help from a local pharmacist who provided me with a clear medication schedule and explained the potential side effects to watch out for.....P₁₀.

.....My elderly parent had difficulty swallowing certain pills, so administering medication orally was a challenge. With the guidance of the healthcare provider, I explored alternative forms such as liquid or crushed forms for easier consumption. I also practiced using a pill-swallowing aid and ensured they took the medication with enough water or a soft food item like yogurt....P₁₂

Keeping track of the various medications and their specific storage requirements was overwhelming. To tackle it, I attached labels with instructions on each medication bottle and stored them in a portable medication organizer. This helped me stay organized and ensured that medications were easily accessible whenever needed.....P₃.

Transportation Challenges

The study participants have expressed their frustration and difficulty in accessing transportation services in Mekelle city, especially during emergencies. The war in Tigray has exacerbated the problem, causing a lack of reliable transportation and a decrease in ambulance services. The taxi drivers prioritize filling up their taxis before taking passengers, which can be life-threatening for elderly relatives in need of immediate healthcare. This situation adds unnecessary stress, anxiety, and challenges for family caregivers trying to ensure timely and appropriate healthcare for their loved ones. The consequences of the war have had far-reaching impacts on transportation services and have significantly affected the well-being of the elderly and their caregivers.

.....Since the devastating war in Tigray, getting transportation service in Mekelle city has become even more difficult. The war has had far-reaching consequences, and one major impact is the lack of reliable transportation. The taxi drivers are hesitant to provide services, and even if they do, they prioritize filling up their taxis first before taking any passengers. This has made it extremely difficult for me to transport my elderly relative to the healthcare facilities when needed...P₅.

.....Before the war, we used to receive ambulance services regularly, which was a great help for caregivers like me. However, after the war, the situation has changed drastically. The consequences of the war have affected the availability of ambulance services in Mekelle city. Now, it is quite challenging to get ambulance service regularly. This has made it even harder for me to ensure that my elderly relative receives timely and appropriate healthcare.....P₁₈

Opinion on Perceived Needs

The perceived needs of family caregivers, as expressed by the participants, revolve around financial assistance, training, access to information, assistance from health professionals. They have expressed that financial assistance would alleviate the burden of expenses associated with caregiving. Access to training programs and workshops would equip caregivers with the necessary skills to provide proper care. Access to reliable and easily accessible information would enable informed decision-making. Consultation and periodic check-ups with health professionals would provide reassurance and guidance.

.....I believe that financial assistance is a crucial need for family caregivers like me. Taking care of the elderly involves various expenses, such as buying medication, hiring caregivers for respite, and providing nutritious meals. Many times, these costs become overwhelming for us, and having some form of financial assistance would greatly alleviate the burden. As a family caregiver, I feel that training is essential..... Often, we lack the necessary knowledge and skills to provide proper care for the elderly, especially when it comes to specific medical conditions or managing difficult behaviors. Access to training programs or workshops would be invaluable, as it would equip us with the necessary tools to ensure the well-being of our elderly loved ones....P₂₁.

.....Having access to information is vital for family caregivers like me. It is often challenging to navigate the complexities of caring for the elderly, especially when it comes to understanding their specific health conditions or finding appropriate resources. Assistance from health professionals is also much needed. While we try our best to care for our elderly relatives, there are often medical needs that go beyond our capabilities. Having health professionals available for consultation or periodic check-ups would be beneficial not only for the elderly but also for us as caregivers, as it would provide reassurance and guidance in providing the best care possible.....P₇

The participants also conveyed their belief that it is necessary to create institutions or specialized residences for the elder population. They expressed that such establishments would offer trained care and assistance, thus lessening the burdensome caregiving responsibilities. Additionally, receiving material aid like necessary supplies would assist family caregivers in ensuring the well-being and security of the elderly within their own homes.

....Establishing institutions or homes for the elderly would greatly address the needs of both family caregivers and the elderly themselves. Sometimes the responsibility of caregiving becomes overwhelming, and we may not have the resources or time to provide the level of care our elderly relatives need..... Having institutions or specialized homes where the elderly can receive professional care and support would give us peace of mind, knowing that our loved ones are in a safe and nurturing environment. Moreover, material assistance, such as providing essential supplies like medical equipment, mobility devices, or home modifications, would greatly assist family caregivers in ensuring the comfort and safety of the elderly at home...P₃.

Discussion

This qualitative study provided valuable insights into the support needs and challenges faced by family caregivers in the care of their elderly relatives at home. The present study highlighted various challenges encountered by the participants and sheds light on the resilience and resourcefulness demonstrated by the caregivers in managing these challenges.

Communication difficulties emerged as a significant challenge, particularly for caregivers dealing with behavioral changes, hearing or speech impairments in their elderly relatives. The participants acknowledged the importance of finding alternative methods of communication, such as written notes, text messages, nonverbal cues, and gestures. These strategies align with previous studies that emphasize the use of simplified language, visual aids, and active listening to improve communication with older adults with cognitive impairments.^{8,9} Such adaptive communication techniques facilitate effective interaction between caregivers and their elderly relatives, enhancing their overall caregiving experience.

Physical distance within the home was another challenge identified by the participants. One participant in the study utilized walkie-talkies and a bell system to overcome this physical distance. While this specific strategy may be unique to the participant's situation, it reflects the innovative approaches employed by family caregivers to improve communication and ensure prompt responsiveness to their elderly relatives' needs. Previous studies have also highlighted the significance of assistive devices and technology in overcoming physical barriers in caregiving.^{10,11}

Financial challenges emerged as a significant concern for the participants, consistent with previous research on the financial burden of caregiving.^{12,13} The strategies employed by the participants to manage the financial burden included budgeting, seeking assistance from community-based organizations, utilizing personal savings, borrowing funds from family members, and exploring government schemes and health insurance options. These strategies align with recommendations from previous studies that emphasize financial planning, seeking available resources, and maximizing available benefits.^{14,15} However, the detrimental impact of the war on the discontinuation of retirement funds significantly restricted the participants' ability to manage the financial burden of caregiving for their elderly loved ones. The

lack of financial resources resulted in difficulties affording essential medications, specialized treatments, and nutritious diets. Additionally, the participants faced limitations in accessing financial aid and subsidized medical services, as the demand for assistance increased due to the war. These findings highlight the urgent need for improved financial support programs targeted specifically for family caregivers in war-affected areas.

Medication management was another challenge highlighted by the study participants, consistent with previous studies on the complexity of medication regimens for elderly individuals.^{16,17} The participants implemented various strategies such as creating charts, setting reminders, seeking guidance from healthcare providers and pharmacists, and organizing medication in portable organizers. These strategies align with recommendations from previous studies that emphasize the importance of medication management tools and guidance from healthcare professionals in ensuring proper administration and storage of medications.^{18,19} However, it is important to note that the participants also expressed frustration and difficulty in accessing transportation services, particularly during emergencies. The war in Tigray has further exacerbated this problem by causing a lack of reliable transportation and a decrease in ambulance services. Taxi drivers prioritizing filling up their taxis before taking passengers further adds to the stress and challenges faced by family caregivers trying to ensure timely and appropriate healthcare for their loved ones. This finding underscores the critical need for improved transportation services and access to emergency healthcare in war-affected areas.

The perceived support needs of family caregivers, as expressed by the participants, encompass financial assistance, training, access to information, assistance from health professionals, and the establishment of institutions or homes for the elderly. These needs align with recommendations from previous studies highlighting the importance of comprehensive support programs for family caregivers.^{20,21} Financial assistance would alleviate the burden of caregiving expenses, and training programs and workshops would equip caregivers with the necessary skills and knowledge. Access to reliable information would facilitate informed decision-making, while regular consultation and check-ups with health professionals would provide guidance and reassurance. The establishment of institutions or specialized homes for the elderly would alleviate the overwhelming responsibility of caregiving and ensure professional care and support for elderly individuals. Material assistance, such as essential supplies, would also support family caregivers in ensuring the comfort and safety of their elderly relatives at home.

Limitation

Qualitative research, by its nature, is subjective as it relies on the perceptions and interpretations of the participants. The study's conclusions are derived from the viewpoints of the participants, and other individuals in similar caregiving roles may have contrasting experiences or give importance to different obstacles. Moreover, in qualitative studies, researchers typically work with a limited number of participants, and the insights gained from their experiences may not reflect those of all family caregivers facing similar circumstances.

Conclusion

The study explored a range of challenges faced by family caregivers in the care of elderly relatives at home. These challenges include communication challenges, financial difficulties, challenges related to medication management, and transportation challenges.

The findings of this qualitative study also highlighted several key support needs of family caregivers in the care of elderly relatives at home. These include financial assistance, training, access to information, assistance from health professionals. Overall, this qualitative study provides valuable insights into the support needs and challenges faced by family caregivers in the care of their elderly relatives at home.

Abbreviations

IRB, Institutional review board; PI, Principal investigator; WHO, World health organization; UN, United Nation.

Data Sharing Statement

The datasets used and/analyzed during the current study available from the corresponding author on a reasonable request.

Ethics Approval and Informed Consent

We have confirmed that our study is conducted in accordance with the declaration of Helsinki. Ethical clearance was obtained from Mekelle University, College of Health Sciences, Institutional review board (IRB). Informed consent was received from the study participants. Participants were fully informed about the study's purpose, procedures, potential risks, and benefits before they decided to participate voluntarily. Participants' personal information and data were kept confidential and only disclosed as required by legal and ethical guidelines.

Consent for Publication

The researchers obtained the participant's consent to publish their responses in a way that protects their anonymity.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflict of interest in this work.

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