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Caring in the Shadows: The Lived Experiences of family Caregivers of Older Adults with Dementia in Fragile and Conflict-Affected Setting in Ethiopia

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Abstract

Background

Family caregiving for older adults with dementia is a complex and demanding role, particularly in low-resource settings. In Ethiopia, limited formal care services, strong cultural expectations, and the lingering effects of conflict place primary responsibility on family members, often without adequate preparation or support. Despite this, there is little empirical evidence on caregivers lived experiences in such contexts.

Aim

This study aimed to explore the lived experiences of family caregivers of older adults with dementia in conflict affecting setting in Ethiopia.

Methods

A qualitative phenomenological design was employed to explore the lived experiences of family caregivers of older adults with dementia in Northern Ethiopia between August 2025 and June 2026. In-depth, semi-structured interviews were carried out with 25 participants.

Results

Four main themes with corresponding sub-themes emerged : (1) The lived embodiment of caregiving responsibility (Transition into the Caregiving Role; Daily Caregiving Routines and Responsibilities; Role Changes and Personal Sacrifices; Disruption of Personal Life Trajectory); (2) The burden of prolonged caregiving (Physical Exhaustion and Health Strain; Financial Hardship and Economic Pressure; Social Isolation and Restricted Life); (3) Caregiving under post-conflict precarity; and (4) Meaning-Making and Identity Transformation.

Conclusion

Caregiving for older adults with dementia in Northern Ethiopia is a totalizing and demanding experience that profoundly affects caregivers' lives. The conflict context further intensifies these challenges, compounding existing social, emotional, and economic burdens. The findings underscore the urgent need for culturally sensitive support systems, caregiver education, and contextually relevant policy interventions to reduce caregiver burden and enhance overall well-being.

Introduction

Dementia is a progressive neurodegenerative condition characterized by deterioration in memory, cognition, and functional ability, significantly impairing individuals' capacity to perform activities of daily living [1]. Globally, an estimated 57 million people were living with dementia in 2021, with nearly

10 million new cases occurring annually, the majority of which are concentrated in low- and middle-income countries [1].

The World Health Organization emphasizes that the impact of dementia extends beyond the individual, profoundly affecting families and informal caregivers, who provide the majority of care globally [1]. Similarly, the Pan American Health Organization highlights dementia as a growing public health priority, with increasing prevalence, rising costs, and significant implications for health systems and social structures [2].

Despite its growing burden, dementia remains underdiagnosed and poorly understood in many settings, contributing to stigma, delayed care, and inadequate support for both patients and caregivers [3–5].

In low-resource contexts, including sub-Saharan Africa, the burden of dementia is further compounded by limited healthcare infrastructure, shortage of trained professionals, and absence of comprehensive national dementia strategies [6–8]. Within these contexts, caregiving responsibilities are predominantly assumed by family members, often without formal training, financial support, or access to appropriate health services [6, 7, 9, 10].

Emerging evidence indicates that family caregivers of individuals with dementia experience substantial multidimensional burden, including physical strain, emotional distress, and economic hardship, particularly in resource-constrained settings [6, 7, 11–13].

In Ethiopia, demographic transitions, increasing life expectancy, and the growing prevalence of chronic conditions are expected to amplify the burden of dementia, yet structured systems to support caregivers remain largely absent [14]. Furthermore, in Northern Ethiopia, the devastating conflict has introduced additional layers of complexity, disrupting healthcare systems, weakening social support networks, and exacerbating the challenges faced by caregivers [15–17].

In particular, there is no known evidence about how caregivers in Northern Ethiopia navigate caregiving responsibilities amid intersecting challenges of dementia, socio-economic hardship, and post-war realities. Therefore, this study aims to explore the lived experiences of family caregivers of older adults with dementia in Northern Ethiopia.

Methods

Study design Area and Period

This study utilized a qualitative research design grounded in a phenomenological approach to investigate the lived experiences of family caregivers of older adults with dementia in three major cities of Northern Ethiopia—Adigrat, Mekelle, and Axum between August 2025 and June 2026.

Source and study Population

The source population comprised all individuals aged 18 years and above who provided care to older adults living with dementia within their household settings. The study population consisted of purposively selected family caregivers who were directly responsible for providing care to older adults with dementia during the study period.

Sampling technique and Sample Size

In this study, a purposive sampling was applied to select participants and the selection focused on individuals with experience in providing care for older adults within their own homes. The participants were identified in coordination with health care professionals, social workers and community mobilizers. The number of participants for the in-depth interviews was guided by the principle of data saturation, whereby data collection continued until no new information or themes emerged. Accordingly, a total of 25 participants were included in the study.

Data collection and analysis

A comprehensive interview guide was developed in English [**supplementary file**] and then translated into the local language, Tigrigna. The semi-structured interview guide was developed specifically for this study based on the study objectives, research questions, and an extensive review of the literature on family caregiving for people living with dementia. The guide was designed to elicit rich descriptions of caregivers lived experiences through broad, open-ended questions and flexible probes. Prior to data collection, the interview guide was reviewed by qualitative research and dementia care experts to assess its content relevance, clarity, and cultural appropriateness. It was subsequently pilot-tested with family caregivers who met the study eligibility criteria but were not included in the final study. Minor revisions were made to improve the wording, sequencing, and clarity of the questions. The recorded interviews were transcribed verbatim and imported into Atlas.ti version 8 for analysis. The transcripts were translated in to English, coded, and organized into categories, leading to the identification of major themes and subthemes.

Results

A. Socio-demographic and caring characteristics study participants

A total of 25 participants were included in the study. Participants were predominantly female. Most were within the younger to middle adult age groups and were married. Educational backgrounds varied, with many having at least primary or secondary education. **[**Table 1**]**

Table 1
Socio-demographic and Caregiving Characteristics of Participants (n = 25)

Variable	Category	Frequency (n)
Age	18–29	6
	30–39	11
	40–49	4
	50–59	3
	≥ 60	1
Sex	Male	9
	Female	16
Marital Status	Single	4
	Married	13
	Divorced	5
	Widowed	3
Educational Status	No formal education	3
	Primary	7
	Secondary	10
	Diploma and above	5
Occupation	Employed	3
	Self-employed	6
	Unemployed	7
	Housewife	9
Relationship to Patient	Daughter	14
	Son	8
	Spouse	3
Residence	Adigrat	6
	Mekelle	12
	Axum	7
Duration of Caregiving	< 1 year	3

Variable	Category	Frequency (n)
	1–3 years	2
	> 3 years	20
Living Arrangement	Living with patient	24
	Not living with patient	1

B. Thematic analysis

Four main themes with corresponding sub-themes emerged from the analysis: (1) The lived embodiment of caregiving responsibility (Transition into the Caregiving Role; Daily Caregiving Routines and Responsibilities; Role Changes and Personal Sacrifices; Disruption of Personal Life Trajectory); (2) The burden of prolonged caregiving (Physical Exhaustion and Health Strain; Emotional Burden and Psychological Fatigue; Financial Hardship and Economic Pressure; Social Isolation and Restricted Life) ; (3) Caregiving in the Shadow of Post-War Crisis; and (4) Meaning-Making and Identity Transformation

1. The lived embodiment of caregiving responsibility

1.1 Transition into the Caregiving Role

Participants consistently depicted the transition into caregiving as abrupt, unstructured, and largely unarticulated. Rather than being a deliberate or negotiated process, entry into the caregiving role often occurred in response to the progressive cognitive and functional decline of the older adult. This transition was shaped less by individual choice and more by entrenched cultural expectations, gendered norms, and the absence of accessible formal care services. As a result, caregivers frequently assumed their roles without prior preparation, guidance, or explicit acknowledgment from other family members. For many, this shift was experienced as sudden and definitive, marked by a moment in which responsibility became implicitly assigned rather than openly discussed.

“There was no discussion… (shrugs softly) … it just happened. One day, everyone was looking at me because I am the daughter, and it was just understood that I would take care of everything. No one really asked if I was ready… if I had other things I needed to do. It all changed very quickly, and I had to adjust, even though inside I felt unprepared.” (P02, Female, 34y, Daughter)

For other participants, the transition unfolded more gradually, yet was no less transformative. Early signs of cognitive decline, such as forgetfulness or misplacing items, initially appeared manageable. However, as the condition progressed, these seemingly minor challenges escalated into pervasive care demands requiring constant vigilance and supervision. Over time, caregiving expanded to occupy the entirety of the caregiver’s daily life:

“At first, it was just small things… forgetting names, losing things, and we did not think much of it. But little by little… (shakes head) … it became worse and he needed more help all the time. Now I cannot leave him even for a short time… (sighs)… because he depends on me for almost everything, and I am always worried about what might happen if I am not there.” (P04, Female, 36y, Daughter)

1.2 Daily Caregiving Routines and Responsibilities

Caregiving was consistently described as an unremitting, round-the-clock commitment that demanded sustained physical effort, continuous emotional engagement, and ongoing situational adaptation. Participants’ accounts illustrate that caregiving extended far beyond discrete tasks, instead constituting a pervasive structure that organized the entirety of daily life. Routine activities were not only repetitive but also intensified by the progressive and unpredictable nature of dementia, requiring caregivers to remain constantly attentive and responsive. Participants portrayed their daily routines as highly regimented around the needs and rhythms of the older adult, often leaving little room for personal choice, rest, or self-care. The temporal structure of the day was dictated by caregiving demands, beginning early in the morning and extending into the night without clear boundaries between periods of activity and rest.

“Oh! my day starts before sunrise … I clean him, prepare his food, give his medicine, and keep watching him all day. I cannot leave him alone, even for a short time, because there is always something to do. Even at night… (shakes head) … I wake up again and again to check on him… ” (P03, Male, 38y, Son)

Beyond the physical workload, caregiving required sustained emotional vigilance. Participants emphasized that the fluctuating and often unpredictable manifestations of dementia—such as behavioral changes, refusal of care, or wandering—complicated even routine tasks. This unpredictability necessitated constant monitoring and rapid adjustment to emerging situations, as illustrated by one caregiver:

“…Sometimes she tries to leave the house… sometimes she refuses to eat… you must always be alert. When she moves toward the door…(silence)… I have to follow her quickly because she does not remember where she is going or how to return.” (P06, Female,41y, Daughter)

1.3 Role Changes and Personal Sacrifices

Caregiving profoundly reconfigured participants’ roles within both the family and the broader social context. What was initially perceived as a temporary responsibility gradually evolved into a full-time, enduring commitment that displaced previous roles and responsibilities. Participants described a transition from being economically active, socially engaged, and personally autonomous individuals to assuming an all-consuming caregiving identity. This shift often came at considerable personal cost, including loss of income, reduced social participation, and diminished personal well-being. Participants emphasized the necessity of withdrawing from paid employment in order to meet the continuous

demands of caregiving. This decision was rarely voluntary, but rather driven by the absence of alternative care arrangements and the intensity of the older adult's needs. As one participant explained:

"I had to stop working to stay with her… (looks down) … because there was no one else. I knew it would make things harder for us financially, but I had no choice. Now we struggle to manage… (sighs)… but I cannot leave her alone because she needs me all the time." (P05, Female, 35y, Daughter)

Beyond economic sacrifices, participants described a gradual withdrawal from social life, marked by reduced participation in community activities and weakening interpersonal relationships. Social isolation was not always a deliberate choice but often a consequence of time constraints, fatigue, and the unpredictability of caregiving demands. One participant reflected:

"Before, I used to attend community… gatherings regularly and visit friends, and I felt connected to others in my community. Now, I am always at home because… I cannot leave the person I care for alone ... over time, people have stopped inviting me, perhaps because they think I am no longer available or because I often decline." (P07, Female,41y, Daughter)

Gendered expectations further intensified these role changes, particularly for female caregivers who were culturally positioned as primary providers of care. Participants highlighted how caregiving responsibilities were normalized and expected, regardless of their physical or emotional condition:

"As a woman… (head lowered), it is expected that I take on this caregiving role without question. Even if I am tired, even if I am sick, there is no alternative…it is my responsibility. People assume that I should continue, regardless of how I feel, and this expectation makes it difficult to express my own needs or limitations." (P09, Female,42y, Daughter)

1.4 Disruption of Personal Life Trajectory

Participants vividly described caregiving as a disruptive force that significantly altered their anticipated life trajectories. Plans related to education, employment, and personal development were often interrupted or indefinitely postponed, as caregiving responsibilities took precedence over individual aspirations. This disruption was not experienced as a temporary pause but rather as an ongoing condition of uncertainty and constraint. For many participants, caregiving required them to abandon educational or career opportunities, often at critical points in their personal development. The lack of alternative caregiving support meant that such decisions were perceived as unavoidable.

"…I had plans to continue my education and improve my future, but I had to stop because there was no one else to take care of him… (worried expression) … even though I wanted to continue, I could not balance both responsibilities, and caregiving became the priority..." (P01, Female,26y, Daughter)

One participant described a narrowing of future-oriented thinking, as the demands of daily caregiving shifted his focus toward immediate survival rather than long-term planning:

“I used to think about my future and how to build a better life for myself and my family. Now, my focus has changed completely—I only think about today, how to manage the situation, and how to survive each day with the responsibilities I have.” (P01, Male,34y, Son)

2. The Burden of prolonged caregiving

2.1 Physical Exhaustion and Health Strain

Caregivers consistently articulated experiences of intense physical fatigue, arising from the relentless and demanding nature of caregiving tasks, often carried out without respite or external assistance. Their responsibilities extended beyond routine support to include physically taxing activities such as lifting and repositioning care recipients, assisting with mobility, managing personal hygiene, and maintaining constant vigilance to ensure safety. These tasks, performed repeatedly over extended periods, resulted in cumulative bodily strain and chronic exhaustion.

“My body is always tired, it is like the tiredness never leaves me. Even when… I try to rest or sleep, I still feel exhausted. I wake up many times at night to check on him, to see if he is breathing well or if he needs something. There is no full rest for me anymore, not during the day and not at night.” (P08, Female,51y, Daughter)

Sleep disruption emerged as a pervasive and distressing concern, with caregivers reporting fragmented, light, and insufficient sleep due to the unpredictable behaviors and needs of care recipients. Many described a constant state of alertness, even during supposed rest periods, reflecting the inability to disengage from caregiving responsibilities.

“Ah!..at night, I cannot sleep deeply because she may wake up confused… or try to go outside without knowing where she is going… (worried expression). Sometimes she calls my name, sometimes she tries to open the door. I am always listening, even when I close my eyes. My sleep is never peaceful… I am always half awake.” (P11, Female,41y, Daughter)

For several participants, the prolonged physical demands of caregiving contributed to a noticeable decline in their own health status. Chronic pain, fatigue-related symptoms, and untreated health conditions were commonly reported. Despite these challenges, caregivers often delayed or avoided seeking medical attention for themselves, citing time constraints, prioritization of the care recipient’s needs, and lack of alternative caregiving support.

“I have back pain from lifting her every day and helping her move from the bed to the chair…(silence)… Some days the pain is very strong, and I feel like I cannot continue… but there is no one else to help me. I do not go to the clinic because there is no time, and even if I go, who will stay with her? So, I just continue… like this.” (P12, Female,38y, Son)

2.2 Emotional Burden and Psychological Fatigue

Beyond the visible physical demands, participants described caregiving as an emotionally taxing experience characterized by persistent psychological fatigue, distress, and internal conflict. Their narratives revealed a complex emotional landscape shaped by prolonged exposure to suffering, uncertainty, and the progressive decline of their loved ones. Caregivers frequently reported feelings of sadness, frustration, anxiety, and helplessness, often occurring simultaneously and intensifying over time. This emotional burden was not episodic but continuous, reflecting the enduring and unpredictable nature of caregiving. A particularly distressing aspect for many caregivers was witnessing the cognitive and functional deterioration of their loved ones, especially in cases involving memory loss and confusion. The gradual loss of recognition and communication was described as deeply painful and emotionally destabilizing.

"It is painful… to see someone you love forgetting everything… (voice lowers) … sometimes she does not even recognize me. She looks at me like… I am a stranger, and that hurts deeply inside. I remember how she used to care for me, and now she cannot even say my name. It feels like I am losing her little by little." (P02, Male,45y, Spouse)

Feelings of emotional depletion were strongly linked to the unrelenting and repetitive nature of caregiving responsibilities. Participants described caregiving as an ongoing cycle without pause, where each day mirrored the previous one, leaving little room for emotional recovery or relief.

"...every day is the same struggle. From morning until night, it is the same routine, the same problems, the same worries. There is no break, no time to relax or think about something else. After some time, it becomes heavy in the mind…like a weight that does not go away." (P06, Female,41y, Daughter)

Caregivers also expressed a profound internal tension between their perceived sense of duty and their growing emotional exhaustion. While many viewed caregiving as a moral, familial, or cultural obligation, this sense of responsibility often conflicted with their own psychological limits, creating feelings of ambivalence and silent distress.

"I know it is my responsibility to take care of him, and I accept that. But inside, I feel very tired… (eyes tearful) ... not just in my body, but in my mind. Sometimes I feel like I cannot continue like this, but I have no choice. I keep going because there is no one else." (P16, Female,28y, Daughter)

2.3 Financial Hardship and Economic Pressure

Caregiving responsibilities imposed a substantial financial burden on participants, particularly within a context where economic resources were already constrained. Many caregivers described a significant disruption to their livelihoods, as the demands of caregiving required them to reduce working hours or completely withdraw from income-generating activities. This resulted in a dual strain: declining household income alongside rising caregiving-related expenses. The financial impact was not temporary but cumulative, intensifying as caregiving needs increased over time.

"…before, I was working and supporting the family. I had my own income and could manage the household needs. Now, I stay at home all the time to care for her… there is no income anymore, but the expenses are increasing every day. It feels like everything is going in one direction." (P14, Male,45y, Spouse)

Participants frequently highlighted the growing costs associated with caregiving, including expenditures on medications, transportation to health facilities, specialized food, and other daily necessities. These recurring expenses placed continuous pressure on already limited financial resources, often forcing caregivers to prioritize essential needs while neglecting others.

"Medication, food, transport…it all needs money… (shakes head) … and these are not things you can avoid. Every week there is something to buy, something to pay for, but we do not have enough. Sometimes we must choose what is more important and leave the rest." (P16, Male,38y, Son)

2.4 Social Isolation and Restricted Life

Caregivers reported profound changes in their social lives, characterized by reduced participation in community activities and a gradual withdrawal from interpersonal relationships. This social isolation was not typically a voluntary decision but rather an unintended consequence of the constant and demanding nature of caregiving responsibilities. Participants described how their roles confined them physically to the home and socially to a limited sphere of interaction centered around the care recipient.

"I rarely leave the house now. Even when… I want to visit friends or go to family gatherings; I cannot go because there is no one to stay with him. Even when I think about going… my mind is still with him, wondering if he is safe. So, most of the time, I just stay at home… (sighs softly)." (P21, Male, 61y, Spouse)

The restriction extended beyond casual interactions to include meaningful cultural and community engagements, which were once integral to participants' identities and social belonging. Missing such events contributed to a growing sense of disconnection and loss.

"Before, I used to go to gatherings, ceremonies, and community meetings… (faint smile) … it was part of my life, and I enjoyed being with people. Now, I only hear about those things from others, and I am no longer part of them… (looks away)." (P02, Male, 33y, Son)

3. Caregiving under post-conflict precarity

Caregiving unfolded within a landscape profoundly reshaped by conflict, where the consequences of war extended far beyond immediate violence to restructure the very conditions of everyday life and care. Participants described a post-war environment characterized by fragility, disruption, and uncertainty, where caregiving responsibilities were continuously negotiated under constrained and often deteriorating circumstances. In this context, caregiving was experienced as taking place "in the shadow" of conflict—situated within damaged health systems, weakened infrastructure, fractured social networks, and a persistent sense of insecurity. Rather than a stable or supportive environment, the post-conflict

setting emerged as an additional layer of vulnerability that intensified an already demanding caregiving role.

"During the conflict, everything stopped… transport, clinics, even food was hard to find. Caring for him became almost impossible. We were… just trying to get through each day… (shakes head) … proper care was not even something we could think about then." (P13, Male, 28y, Son)

"…there were times when I could not get his medication. I searched in many places, but there was nothing available. I had to watch his condition worsen without being able to help him, and that feeling was very painful… (sighs)… like my hands were tied." (P04, Female,36y, Daughter)

Importantly, participants stressed that these disruptions did not fully resolve after the cessation of active conflict. Instead, the post-war period was characterized by partial recovery, instability, and ongoing shortages, which continued to affect caregiving capacity and access to services.

"Even now, services are not fully back. You go to the health center, and sometimes there is no medicine, no staff, or… they tell you to come another day. You just return home the same way you went … nothing has really stabilized." (P20, Female,29y, Spouse)

Experiences of loss and displacement emerged as central and deeply transformative elements of participants' narratives. Many caregivers described being forcibly displaced from their homes, losing property, livelihoods, and community connections. These losses compounded caregiving responsibilities by removing the material and emotional foundations that previously supported family life.

"We were displaced from our home… (voice lowers) … everything we built was gone in a short time. We lost our house, our belongings, our stability. Starting again while caring for him is extremely difficult because you are rebuilding life while also providing constant care." (P23, Male,36y, Son)

One participant described the death or absence of family member who had previously shared caregiving responsibilities. This loss of informal support networks significantly increased caregiving burden and emotional strain, leaving the person to manage responsibilities alone.

"My brother used to help me with his care, especially when I needed to go out or rest. But we lost him during the conflict… (eyes tearing up) … and after that, everything fell on me. Since then, I have carried it alone." (P24, Male, 37y, Daughter)

4. Meaning-Making and Identity Transformation

Participants' narratives revealed caregiving as a profoundly interpretive and identity-shaping experience through which individuals continuously constructed meaning around their roles, responsibilities, and evolving sense of self. Beyond its physical, emotional, and financial demands, caregiving emerged as a deeply lived process of meaning-making in which participants actively negotiated personal values, cultural expectations, moral beliefs, and relational obligations. In this context, caregiving was not merely

an activity performed in response to need; rather, it became an existential position that gradually reshaped who participants understood themselves to be. Many described a slow and often imperceptible transformation in which “doing care” evolved into “being a caregiver,” with this identity increasingly defining their daily existence, social recognition, and internal self-concept.

“He is my father… it is my duty to care for him. No matter how difficult it is, I cannot turn away. Even if I am tired or stressed, I remind myself that this is what I must do as a child. That sense of responsibility keeps me going… even on days when the burden feels more than I can manage.” (P06, Male,38y, Son)

“Sometimes I feel very tired and overwhelmed, especially on difficult days… (pauses, reflecting). But when I remind myself why I am doing this…that he depends on me, and there is no one else—it gives me the strength to continue. Somehow… (nods slowly) … that thought helps me keep going, because without it, I do not think I could manage.” (P11, Female, 40y, Daughter)

A particularly salient theme within these narratives was endurance, which emerged as a defining feature of the caregiving experience. Endurance was not described as a deliberate heroic act, but rather as a quiet, continuous form of survival and persistence shaped by necessity, responsibility, and relational commitment. Caregivers often emphasized that continuation was less a choice than an unavoidable reality.

“You continue because there is no alternative… (long pause) … stopping is not something you think about. Life does not give you another option, so you just keep going, day after day, even when you are tired.” (P25, Female,35y, Son)

Discussion

The lived reality of caregiving in this study reflects a gradual transformation of individuals into caregivers through a process that is often unstructured, unprepared, and socially expected. Participants assumed caregiving responsibilities suddenly or incrementally, without formal training or institutional support, consistent with evidence from other Sub-Saharan African contexts where dementia care is predominantly family-based and informal [18, 19]. Similar findings have been reported in Ghana and Uganda, where caregiving transitions are shaped by cultural obligation and lack of formal care alternatives [20, 19].

Daily caregiving routines in this study were characterized by continuous physical labor, emotional vigilance, and temporal disorganization. Caregivers described caregiving as a round-the-clock responsibility with no clear separation between rest and duty, congruent with previous African studies, which also emphasize caregiving as a totalizing role that reorganizes everyday life [21–24].

Similar patterns are observed in Asia, particularly in China and India, where behavioral and psychological symptoms of dementia require constant supervision and management [25–28]. However, unlike in high-income countries where respite services, home nursing, and assistive technologies are more accessible,

caregivers in Ethiopia lacked institutional support, leading to heightened exhaustion and loss of personal autonomy. The concept of “temporal confinement” observed in this study aligns with global caregiving literature, which describes time as being restructured around the needs of the care recipient rather than the caregiver’s own life [3].

Role changes and personal sacrifices were profound and multidimensional, involving withdrawal from employment, education, and social participation. These findings are consistent with global evidence indicating that dementia caregiving leads to significant role displacement, particularly in low- and middle-income countries [29–32]. In Latin America, similar disruptions are reported, although some countries such as Brazil and Mexico have introduced limited social protection mechanisms and caregiver allowances that partially mitigate economic loss [33–35]. In contrast, high-income countries such as Sweden and Germany provide caregiver benefits, workplace flexibility, and formal care services that reduce total role displacement, although caregiving burden still persists [36–39].

The “weight of care” theme highlights the multidimensional burden experienced by caregivers, encompassing physical exhaustion, emotional distress, financial strain, and social isolation. Physical strain, including fatigue, sleep deprivation, and musculoskeletal pain, was a dominant experience, consistent with findings from Africa and Asia where caregivers report significant physical health deterioration due to intensive caregiving tasks [6, 9]. Emotional burden was equally profound, characterized by grief, frustration, anticipatory loss, and psychological fatigue. Similar emotional experiences have been documented globally and are often conceptualized as “ambiguous loss,” where caregivers grieve the progressive cognitive decline of a loved one who is physically present but psychologically altered [40–42].

Financial hardship emerged as a critical determinant of caregiver vulnerability. Participants described loss of income due to withdrawal from employment and increased out-of-pocket expenditures for medication, transport, and daily care needs. These findings align with global evidence indicating that dementia imposes catastrophic economic consequences on households in LMICs [13, 43, 44]. In Asia, similar financial pressures are reported, particularly in countries without universal long-term care insurance systems [9]. In Latin America, partial subsidies and pension-based support reduce but do not eliminate financial strain [45, 46].

Social isolation and restricted life were also prominent findings. Caregivers experienced withdrawal from community life, reduced social participation, and declining social networks. This aligns with studies from Sub-Saharan Africa that highlight caregiving as a socially isolating experience due to time constraints and lack of replacement care [20, 18]. Similar findings are reported in Asian contexts such as Japan and South Korea, although structured community-based dementia programs in these countries help maintain caregiver engagement to some extent [47, 48].

A critical and context-specific finding of this study is caregiving in the shadow of conflict. Participants described how the post-war environment disrupted health services, destroyed infrastructure, and

weakened social systems, significantly constraining caregiving capacity. These findings are consistent with studies from Tigray and other conflict-affected regions, which document severe deterioration of health systems and chronic disease care disruption [15–17]. Similar patterns have been observed in humanitarian settings such as Ukraine and Syria, where caregiving occurs under conditions of displacement, insecurity, and health system collapse [49, 50].

Meaning-making and identity transformation emerged as central processes through which caregivers interpreted and sustained their caregiving roles. Caregiving was framed as a moral and cultural duty rooted in filial obligation, consistent with findings from Africa and Asia where family responsibility is a dominant caregiving norm [10, 20]. This moral framing provided psychological resilience and meaning despite hardship [10, 20].

Conclusion

Caregiving emerged as a continuous, multidimensional role that profoundly affected caregivers' physical, emotional, social, and economic well-being. Family caregivers assumed responsibility largely because of cultural obligations and limited formal care services, often sacrificing employment, education, and social participation. The post-conflict context further intensified caregiving challenges through disrupted health services and economic instability. Despite these hardships, caregivers found meaning through cultural values, family bonds, and moral responsibility, fostering resilience and identity transformation while sustaining long-term caregiving roles.

Recommendation

Dementia care should be integrated into primary healthcare to improve early diagnosis, continuity of care, and support for both older adults and their family caregivers. In addition, healthcare professionals should receive training to recognize caregiver burden, provide psychosocial support, and offer practical education on dementia care. Policymakers should also develop comprehensive dementia care strategies that recognize the vital role of family caregivers while strengthening health and social support services, particularly in post-conflict settings. Furthermore, community organizations, religious institutions, and local support networks should work together to increase dementia awareness, reduce stigma, and establish caregiver support groups. At the family level, caregiving responsibilities should be shared more equitably to lessen the physical, emotional, and financial burden on individual caregivers. Finally, future research should evaluate interventions that improve caregiver well-being and explore caregiver experiences across different contexts to inform evidence-based policies and practice.

Limitations of the Study

As a qualitative study, the findings are based on the experiences of a purposively selected group of family caregivers and are therefore not intended to be statistically generalizable to all caregivers of older adults with dementia. In addition, the data relied on participants' self-reported experiences, which may have been influenced by recall bias or social desirability bias.

Declarations

Author Contributions Statement

GNH: Conceptualization, Methodology, Investigation, Data curation, Formal analysis, Project administration, Writing – original draft; **WPC:** Methodology, Validation, Supervision, Writing – review & editing; **GOT:** Formal analysis, Validation, Writing – review & editing; **PASS:** Methodology, Writing – review & editing; **ZAT:** Investigation, Validation, Writing – review & editing; **IVLN**: Software; **CJAS:** Supervision visualization; **SLA**: Supervision: **JSAO:** Supervision All authors have read and approved the final version of the manuscript and agree to be accountable for all aspects of the work.

Declaration of Competing Interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this study

Ethical Declaration

Ethical approval for this study was obtained from the Institutional Review Board (IRB) of Mekell e University. The study was conducted in accordance with the ethical principles of the Declaration of Helsinki. Written informed consent was obtained from all participants prior to data collection. Participants were informed about the purpose of the study, their right to decline participation or withdraw at any time without any consequences, and the measures taken to ensure confidentiality and anonymity. All interview recordings and transcripts were securely stored and accessed only by the research team.

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Data Sharing

The datasets generated and/or analyzed during the current study are not publicly available because they contain identifiable qualitative data that could compromise participant confidentiality. De-identified data may be made available by the corresponding author upon reasonable request, subject to approval by the relevant ethics committee and in accordance with institutional and ethical requirements.

Consent for publication

Not applicable. The manuscript does not contain any individual person's identifiable data, images, or other information requiring consent for publication.

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