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Balancing burden and bond: challenges and motivations of family caregivers of patients with end-stage liver disease in Northern Ghana—a qualitative inquiry

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ABSTRACT

Objective This study explored the burdens and motivations of family caregivers (FCs) for patients with end-stage liver disease (ESLD) in a tertiary hospital in Ghana.

Design A qualitative exploratory, descriptive approach with a purposive sampling technique was adopted. Data were collected through face-to-face semi-structured interviews. The interviews were audio-recorded, transcribed verbatim and analysed using content analysis.

Setting Participants were recruited from a tertiary hospital in the Northern Region of Ghana.

Participants 15 FCs aged between 18 and 50 years caring for patients with ESLD were recruited.

Results The study's findings revealed that FCs of individuals with ESLD encountered considerable challenges, including sleep deprivation, physical exhaustion, family conflicts, financial difficulties and social restrictions. These difficulties contributed to a sense of being overwhelmed as caregivers strived to fulfil their duties. Family bonds, reciprocal relationships and religious obligations were the motivation/driving force for FCs caring for relatives with ESLD.

Conclusion Integrating palliative care services in tertiary health facilities will reduce the burdens FCs of patients with ESLD face. Relevant stakeholders in the health sector need to develop culturally sensitive interventions to support FCs caring for patients with ESLD in Ghana.

STRENGTHS AND LIMITATIONS OF THE STUDY

- ⇒ This study offers an in-depth and inclusive account of the burdens and motivations of family caregivers (FCs) of individuals with end-stage liver disease through qualitative interviews and provides valuable insights into their experiences.
- ⇒ A heterogeneous group of FCs with varying ages, gender, religious backgrounds and socio-economic status was recruited, allowing for a comprehensive exploration of the diverse experiences of FCs.
- ⇒ Retrospective interviews may have introduced recall bias, which could lead to an overrepresentation of FCs experiencing more significant burdens and lower quality of life.
- ⇒ The study's findings cannot be generalised due to socio-economic and cultural differences in Ghana, as participants were selected from northern Ghana.

INTRODUCTION

End-stage liver disease (ESLD) is an advanced stage of liver disease caused by chronic liver damage, characterised by permanent liver scarring resulting from chronic inflammation and/or injury.[1 2] ESLD leads to liver architecture disruptions due to the formation of large nodules, reorganisation of the vascular system, neo-angiogenesis and deposition of an extracellular matrix.[3] Cirrhosis-related ESLD is deadly and causes excruciating physical and emotional pain in the absence of a liver transplant.[4]

In sub-Saharan Africa (SSA), where viral hepatitis B is a key risk factor, ESLD poses a significant public health burden.[5 6] The prevalence of ESLD in the region is on the rise, with over 38 000 new cases of primary liver cancer diagnosed in 2020.[7] Over 80% of hepatocellular carcinoma (HCC) cases worldwide are found in SSA.[8] The most common risk factor for HCC, especially in West Africa, is chronic hepatitis B virus infection; the highest incidence of HCC is found in Guinea and Gambia.[8]

Providing care for family members with advanced disease, especially in resource-limited settings, poses practical and emotional challenges due to insufficient palliative care institutions.[9] Family caregiver (FC) burden is "the extent to which caregivers perceive the adverse effect of caregiving on their emotional, social, financial, and physical functioning".[10] For example, FCs face severe financial strains, challenges managing disruptive patients and unmanageable patient emotions, limited social and personal entertainment, stigma and isolation and less time for full- or part-time work.[11 12]

In Ghana, caregiving is considered part of the informal care system and has not received the needed attention. The historically collectivist practice of caregiving is diminishing due to societal changes like urbanisation and unfavourable economic conditions, leading to an increased burden of caregiving.[13 14] Despite patients with ESLD presenting at an early age with significantly advanced disease in Ghana, there is limited research on the burden faced by FCs.[7] Understanding FCs' burden in providing care to individuals living with ESLD will provide insights into developing tailored interventions and programmes to support those families. Therefore, this study sought to address these research gaps by exploring the burden experienced by FCs of individuals with ESLD in Ghana.

METHODS

Study design

An exploratory, descriptive qualitative approach was used to explore the perspectives of burden among FCs of patients living with ESLD and their motivations for care provision. An exploratory design was used, given the lack of previous research investigating the burdens and motivations of FCs of ESLD in SSA, specifically Ghana.

Study setting

The study was conducted at Tamale Teaching Hospital (TTH), the largest hospital in northern Ghana with a bed capacity of 800. It serves a catchment area comprising about 2.5 million people. TTH was established as a medical referral centre to cater for several regions in Ghana. Additionally, it serves neighbouring countries, including Côte d'Ivoire, Burkina Faso and Togo. TTH has a specialised unit for internal medicine (endocrinology) where patients diagnosed with ESLD are managed.

Study population

FCs of patients diagnosed with ESLD in the Northern Region of Ghana were the target population for this study. The study recruited FCs to provide care to patients with ESLD admitted to the ward. The ward in-charge identified eligible FCs and facilitated recruitment. The ward-in-charge informed FCs staying with the patients admitted to the ward about the study. They were given study details, and interested FCs were directed to meet the first author at the ward-in-charge's office. The first author thoroughly explained the study's purpose and procedures and **the informed consent process** before obtaining consent.

Participant eligibility

Inclusion criteria

FCs aged 18 years and above who provided unpaid assistance to a patient with an ESLD diagnosis.

Exclusion criteria

FCs of patients with liver conditions such as viral hepatitis B, hepatitis C and non-alcoholic fatty liver disease. FCs of patients with ESLD receiving outpatient department services.

Sampling method and sample size

A purposive sampling technique was used to recruit participants who met the inclusion criteria.[15] This helped to enrol participants who had experienced the phenomenon under study. The first author contacted potential participants face-to-face and explained the purpose of the study to them after study approval from the hospital's management. Only FCs who voluntarily consented to participate in the study were recruited. The notion of data saturation informed the sample size, enabling the researchers to concentrate on obtaining varied information.

Data collection tool and procedure

Face-to-face in-depth interviews using a semi-structured interview guide (refer to online supplemental appendix S1) were used to collect data.[16] Data collection occurred between January and March 2022. The interviews took place in the ward-in-charge's office, chosen for its convenience and conducive atmosphere for the participants, and mainly in the afternoons when the ward was less busy. All the participants consented to the study by signing (12 participants) or thumb-printing (three participants). In total, 15 in-depth interviews were primarily conducted in English (10) and Twi (5), with each session lasting between 45 and 60 min. During the interview, open-ended questions with probes were used to allow the participants to express themselves fully, and the interviews were audio-recorded. Field notes were taken during and after the interviews. Data saturation was confirmed after the 15th interview (the first author, JDD, with post-graduate research experience, perceived that the interviews' content was becoming redundant and that no new information was being revealed); two more interviews were conducted to ensure saturation had been reached but were not added to the analysis. The interviews were facilitated by the first author (JDD), who has post-graduate research experience.

Data analysis and management

The first author manually conducted data analysis concurrently with data collection using thematic content analysis. At the end of each interview, the first author manually transcribed the audiotape recording verbatim into written words to facilitate analysis. Five interviews were conducted in a local dialect, Twi, first transcribed in Twi by the fourth author and then translated into English by the fifth author. The remaining ten were conducted in English. The translated versions of the interviews were discussed with the third and fifth authors, who are both fluent in Twi and English, to ensure the accuracy of the transcribed data. The thematic analysis approach by Braun and Clarke[17] was used for data analysis as follows:

Phase 1

After reading each transcript multiple times, the first and second authors became familiarised with the data and developed a preliminary list of ideas.

Phase 2

The two authors developed preliminary codes from the data and organised data pertinent to each code. They deliberated on codes, and disagreements were reconciled.

Phase 3

Themes were found by aggregating codes into prospective themes and compiling all pertinent data associated with each recognised theme.

Phase 4

The authors reviewed the themes, consolidating some and modifying others.

Phase 5

Themes were defined, refined and named.

Phase 6

Subsequently, a report was prepared using the data to succinctly, coherently and logically convey the caregiving burdens and motivations of FCs of people with ESLD.

Transcripts were anonymised by removing participants' actual names and substituting them with designated codes, such as family caregiver (FC), followed by numerical identifiers. The authors had exclusive access to the interview sessions. The files were secured on a password-protected computer.

Rigor

Rigor addressed credibility, transferability, conformability and dependability in the study using Lincoln and Guba's approach.[18] To ensure credibility, member checking was done immediately after the interview, where key points were summarised, and audio recordings were replayed for participants to verify their responses. Transcripts were provided the next day to allow participants to review and confirm that they accurately reflected their views. An accurate and detailed account of the research context and participants' backgrounds, data collection and study findings was explicitly provided to achieve transferability. The data were coded and categorised into major and subthemes to ensure confirmability. The researchers' comprehensive account of each stage of the research process and the transparent data analysis process accomplished the study's dependability.

Findings

This study's participants were 15 FCs who provided care to their relatives admitted to the TTH with ESLD.

Table 1 Socio-demographic profile of participants

Family caregiver (FC)	Age	Marital status	Relationship to patient
FC1	Mid-20s	Single	Sibling
FC2	Early 20s	Single	Grandchild
FC3	Early 40s	Married	Sibling
FC4	Mid-30s	Married	Child
FC5	Early 40s	Married	Sibling
FC6	Mid-30s	Married	Sibling
FC7	Mid-20s	Single	Sibling
FC8	Late teens	Single	Child
FC9	Early 30s	Married	In-law
FC10	Mid-30s	Married	Child
FC11	Early 20s	Single	Niece
FC12	Early 50s	Married	Sibling
FC13	Late 30s	Married	Child
FC14	Mid-30s	Married	Spouse
FC15	Early 20s	Single	Child

Participant characteristics

The majority of the participants (n=10) were males, were married (n=9) and were working (n=12). Most of the participants reported religious affiliation with Islam (n=9) and were >30 years old (n=9) (see table 1).

Themes of the study

Thematic content analysis yielded two main and seven themes: FCs' burden and FCs' motivation. The themes and their sub-themes are shown in table 2.

FCs' burden

This theme encompasses the physical, financial, psychological and social stress that comes with providing care to a family member who has been diagnosed with ESLD. It highlights the profound challenges faced by caregivers as they navigate the demands of caregiving.

Physical burden

This sub-theme outlines the physical toll of caregiving on FCs, mainly due to the frailty associated with ESLD. Physical burden is imposed by the direct demands placed

Table 2 Summary of themes and sub-themes of this study

Themes	Sub-theme
FCs' burden	Physical burden Economic burden Psychological burden Social burden
FC's motivation	Reciprocity Socio-cultural obligation Religious obligation

FC, family caregiver.

on FCs by patients' inability to perform physical activities such as bathing, walking without assistance and grooming. Participants reported assisting patients with these daily activities as integral to their caregiving role.

> She cannot do anything by herself, everything depends on me. I carry her to the washrooms and bathe her as well, groom her, clean her mouth, feed her and even assist the nurses in changing her position in bed so it is not easy for me at all. (**FC3**)

Similarly, FCs indicated they faced fatigue from high-energy caregiving duties, particularly when care recipients were highly dependent. Running errands for medications, wound dressings and food added to their direct caregiving tasks. The non-functional lift in the hospital facilities forced participants to climb numerous stairs and cover long distances, contributing to exhaustion and stress. Additionally, the need to search for prescribed items in different locations increased the physical demands on FCs.

> … every morning, I make sure she bathes, changes her clothes, gets her food, and feeds her, if blood samples are taken, I take them to the lab for the investigation and I carry out the activities of daily living. My patient is on the third floor and the elevator isn't working so I came down for medical supplies using the stairs and that is tiring. (**FC4**)
>
> … my patient feels very weak and is unable to perform any activity because of the abdominal distention and significant weight loss, I therefore work more than my strength. I feel tired because I am not used to this type of stress…it is just too much for me. (**FC11**)

FCs frequently reported experiencing health issues associated with their caregiving role. These problems encompassed general body pain, sleep disturbances, fatigue, a gradual decline in physical abilities and increased susceptibility to infections such as malaria. A male caregiver, responsible for his mother's care, specifically noted contracting malaria due to continuous exposure to mosquitoes in the hospital environment. He narrated his experience as follows.

> My physical abilities have declined over time… can you imagine staying in the hospital overnight outside? Because my mother is in the female's ward anytime the nurse comes to perform procedures on the other patients, they drive me away. I have been sleeping in the open and mosquitoes have been "chewing (biting)" me till daybreak. I am currently battling with malaria and on malaria treatment. (**FC4**)

Some FCs opted to spend the night in the hospital so that they could offer the required assistance when it was required. However, they found this challenging because the hospital lacked accommodations for caregivers. Other FCs reported that they resorted to sleeping outside the wards, sometimes on the floor or in chairs close to the patient's bedside, which they indicated affected their overall health.

> I do not have a place to sleep because the security always drives us, the caregivers out of the ward at night. So, we sleep outside on the floor of the veranda, and I know I will fall sick because of the exposure to cold weather and mosquitoes. (**FC2**)

Likewise, FCs stated that the frequent waking up to check on their patients and the constant thinking about the outcome of their patients' conditions were factors that hindered their ability to sleep well.

> I wake up multiple times in the night to check on the patient and at times the nurses come to work on her, which normally awakes me. I have developed a headache, and I think it is a result of my interrupted sleep. I am even afraid that I might get hypertension, but the last time I checked my blood pressure was within the normal limits. (**FC4**)

On the other hand, participants found it challenging to stay continuously on the hospital premises because they needed to balance their regular jobs with caregiving responsibilities. Early awakening was an equally significant factor reported by caregivers to have affected their sleep patterns. Caregivers who slept at home needed to report to the hospital early enough to perform their roles before the nurses and doctors commenced their work on the patient.

> …because the up and down, travelling every dawn from Saboba to Tamale and back is not a small journey… about 100miles. I normally wake up very early so that I can come to the hospital to bathe the patient, change her clothes and feed her before they drive us (caregivers) out of the ward. I feel fatigued most times so my role as a caregiver is affecting my physical health. (**FC12**)

Another FC intimated that his care receiver's failure to perform their activities of daily living (ADLs) added to his sleep deprivation. He reported having an intermittent sleep pattern because of addressing the needs of the patients during nighttime.

> … the patient cannot do anything by himself, so everything depends on me, I bathe him, brush his teeth and so on even at night I wake up frequently to cater to the patient's calls. (**FC7**)

Additionally, the distress of a loved one because of the sickness was cited by participants to affect their sleep patterns.

> … I was able to sleep up until 3 a.m. when I woke up at 3 a.m. I could not close my eyes again; my mind was just on her because no one was there to sleep with her. So, I was just there thinking now how is the condition…how is the condition now? (**FC3**)

According to some participants, their inability to sleep was the cause of specific health challenges they had. Headache and development of hypertension were some conditions attributed to their inability to sleep well. This is contained in the following narratives. A male caregiver feared his inability to find a comfortable place to sleep accounts for the headache he is suffering and could also lead to the development of hypertension.

> The hospital environment is not a place you sleep very well I do not have a bed here, so I sit overnight without closing my eyes. At times I just take a nap for 2-3 hours and return. I am developing a headache, and I think it is a result of my inability to sleep well. (**FC4**)
>
> …since my father was admitted I have not had a comfortable bed to sleep on and anyone who has a problem with sleeping will have an impact on the person's health. (**FC15**)

Some FCs stated that the range of activities they undertook as caregivers for the well-being of their patients made them suffer some setbacks in their physical health, including general body pains and pains in the neck regions. A male FC who provided care to his father, diagnosed with ESLD, reported that he experienced pain around his neck due to and fro movement that is associated with his caregiving role.

> Even as I speak with you now… I am experiencing some pains in my neck because I am not used to moving like this and from yesterday up till now, I am not just myself. (**FC10**)

Economic burden

Financial constraints were expressed by nearly all the FCs as a significant burden. FCs reported that they provide financial care to their care recipient from their savings, affecting their finances. Participants stated that their financial difficulty was linked to various treatment expenses, including medicines, diagnostic tests, diapers and non-medical costs, such as transportation to and from the hospital and the referral centres and buying food. This was a significant obstacle, as demonstrated by claims made by some of the respondents, who stated the following:

> Financially, it has affected me in the sense that some things I did not budget for end up spending on them, I normally draw my budget at the end of the month thus what I will spend and the amount I will save but as of now I am eroding my savings to provide care to my patient. (**FC9**)

Participants indicated dissatisfaction with the limited coverage of the National Health Insurance Scheme for diagnosing and treating patients with ESLD. This led to out-of-pocket expenses for patients and FCs, who had to pay for OPD cards, folders, consultations, laboratory tests and medications. FCs often had to bear the full cost or provide top-ups before their patients could receive these essential services. An FC responsible for his mother, diagnosed with ESLD, highlighted these challenges.

> In terms of my finances, playing the position of a caretaker has had an impact. Although my mother has active health insurance, I was requested to pay 13.00 cedis for the OPD card and 130.00 for the folder and consultation as soon as we arrived at the records department. Almost all the medications and lab tests have been paid for by me. I am practically paying for all the services provided to my mother. (**FC4**)

In furtherance, FCs, especially those in the informal sector, reported that their inability to generate income while performing their caregiving duties depleted their savings, compelling them to contract loan facilities to care for the patient. Magdalene, an FC providing care to her patient, reported that

> …this caregiving role has affected me very much, my financial situation is nothing to ride home about, I must even take loans and other things to care for him. (**F2**)

FCs who participated in this research also reported sales of personal effects. Some participants stated that they had to sell their personal belongings to pay for some crucial services at the hospital. A male FC disclosed that he sold some personal belongings to support the treatment of the care recipient's condition.

> Certain times, you pick items from your house and sell them to support in my care recipient treatment. If I sell my property to take care of him and he recovers from the sickness, it is better than the physical wealth. (**FC12**)

Another factor that FCs cited as adding to their financial constraints is non-treatment costs, such as transportation to the hospital and provision for the upkeep of their respective homes, some of which they used to co-perform with the care recipient. One participant narrated that

> … as I am here, I should have been at work to get money to support the family, and you know, women, every morning you have to give something out to keep my family going. (**FC6**)

Additionally, the progressively deteriorating state of health of patients diagnosed with ESLD makes them unable to perform ADLs, therefore requiring continuous assistance from the FC. The accompanying frailty of the patient's condition limits the mobility of the FC relative to attend to their business.

> I am getting a lot of calls from my customers requesting goods but my inability to travel is affecting my business I cannot leave the patient because he is not able to do anything by himself. (**FC15**)

Psychological burden

The psychological burden was reported by FCs as a major strain in caregiving. The diagnosis of ESLD brought enormous mental stress for the FCs since death is imminent.

> She is so dear to my heart but seeing her in this state pains me. I know we are all going to die…I know she will die but I wanted her to enjoy me more because what I want her to get from me, she has not gotten it yet. The work that I do the money there is not enough, I am still investing in myself by paying fees and so on, so I wanted her to have a comfortable life before going to the next world. (**FC10**)

Family care providers are confronted with enormous mental strain watching someone they genuinely love go through pain and discomfort as the condition progresses and the clinical manifestations worsen. The progressive deteriorating nature of ESLD smacks of a wide range of psychological distress, including frustration, fear and a sense of hopelessness or despair among FCs of patients with ESLD. Some FCs experienced frustration because of the lack of improvement in the patient's condition despite their efforts.

> … we are putting in many efforts you know paying the bills, in showing that we care at times we stretch ourselves to serve him with whatever he has the appetite for, the food he wants to eat is what we provide just want to make he takes something small… you know doing all these and not seeing any improvement in the condition is quite frustrating. (**FC9**)

Some FCs reported that the uncooperative behaviours of their care recipients sometimes frustrate them. FCs described their experiences as follows:

> … the patient promised that he would give out some information, vital information, which he has not done, and the wife is continuously asking him to communicate it out and he is not ready for that. (**FC9**)

Participants who did not stay overnight at the health facility with their patients' expressed concerns about the patients' care. They noted that nurses, while present, may not always be attentive to all patients, especially during the night shift when multiple patients need attention. This caused uneasiness for FCs considering leaving their patients to go home to sleep. Despite not being qualified to provide certain services like pain relief, FCs highlighted their presence as a constant reminder to the health team about necessary interventions for the care recipient. One male FC mentioned experiencing daily apprehension and disrupted sleep due to fears about potential problems his patient might face:

> … last night I woke up at 3 a.m. and did not close my eyes again…my mind was just on her because no one was there to sleep with her. So, I was just thinking of how the condition was. I even wanted to return to the hospital at that time, but I later said no let me exercise patience so that after the 5 o'clock prayer then I would come. (**FC10**)

FCs of patients diagnosed with ESLD largely intimated that their inability to help their care recipient whom they see as suffering created a feeling of despair and helplessness within them.

> … my mother has suffered… before this sickness she had some problem with her waist and we brought her to the hospital several times to see the specialist and even to the extent of going to see a herbalist on it and all that, that is why I am saying that she is suffering. (amidst crying) (**FC10**)

The seeming lack of improvement in the care recipient's condition despite the efforts or energy devoted by the caregiver in the caregiving process creates a sense of hopelessness among the caregivers.

> … I will say there has been some deterioration in the care recipient's state of health because since we were at West Hospital the distension of the abdomen was not there but now the abdomen is distended it has come out. So, I think his health is deteriorating. (**FC6**)

Social burden

These are issues that have an impact on the FC's social life. It can range from FC relationships with friends to an inability to participate in social activities. FCs reported that caring responsibilities were performed to the detriment of their social lives. FCs revealed that their involvement in caregiving has denied them the opportunity to attend certain social events such as weddings, funerals, baby-naming ceremonies and parties due to the constant care demands of their care recipients and the distance, as some caregivers are far from the homes where these events are organised.

> I have missed a lot of wedding ceremonies, naming ceremonies, a lot of funerals because most of them are organized when I am with my mother at the hospital providing care and because we travel far to seek healthcare, I cannot leave her to attend such programs back at home. (**FC4**)
>
> My social life has changed, I used to hang out with my friends but now I do not go anywhere apart from going out to buy food and medications I am always at the patient's bedside. Everything has changed I am always here 24 hours. (**FC2**)

FCs reported reduced interactions with family and friends due to time-consuming care and location constraints. Some careers expressed feelings of insecurity about leaving their spouses to take care of the patient at the hospital, which is situated far from their communities. A male caregiver who provided care to his brother satisfactorily articulated this idea.

> Since I assumed this role as a family caregiver to my brother, I have been moving out of my community to this place, my wife is alone at home so the security so far as my marriage is concerned is loose. (**FC3***)*

An FC mentioned that he tries to secure his relationships with friends, especially those whose programmes he is unable to attend, by sending them money through an electronic mobile transfer with a message explaining his inability to attend the function.

> I normally send messages to people who have invited me to their social programs to explain the situation in which I find myself to them followed by some financial commitment to them by giving what I would spend in attending the program to them via e-cash. (**FC4**)

FCs mentioned that their involvement in care delivery prevented them from religious practices. A FC of Islamic faith admitted that although he could say his prayers as required, he was unable to follow strictly certain religious rituals, such as fasting, due to the difficulty in getting food at the hospital at dawn.

> I can pray five times a day but for fasting the challenge here at the hospital is about the food because in the morning you need something to eat before you can fast but at the hospital, I cannot get it hence my inability to fast. (**FC1**)

FC's motivation

This emerging theme explains the driving force behind participants' choice to take on the role of FC for individuals with ESLD. Reciprocity, religiosity and socio-cultural obligations were the underpinning sub-themes of this theme.

Socio-cultural obligation

To begin with, the family is required to provide care to its unwell members because Ghanaian society deems it unacceptable to ignore the sick. According to those who participated in this study, the primary factor motivating FCs to accept the caregiving role was the family's duty to provide for its ailing members. Participants who cohabited with their sick relatives had no option but to bring them to the hospital, leading to their becoming caregivers. This is apparent in the following quote:

> I became a family caregiver because my mother gave birth to only two of us but then the other one is working in Accra, Ghana Immigration headquarters yeah, so I am down here and the only person staying with her. (**FC10**)

Also, FCs in this study reported the parental relationship with the patient as a major motivating factor in their acceptance of the caregiving role. Participants stated that caring for a parent, for instance, was so culturally ingrained that, when the time came, care was provided without question or any other consideration.

> I do not have a choice to make…because she is my biological mother, who is sick. I saw how my mother took care of her parents and the rest of the family anytime they were sick so now that she also needs care, I should be there for her. It is part of our tradition for young ones to care for their parents, so I didn't even think twice about the decision of caring for her. (**FC1**)

In addition, the spousal relationship among some cultures in northern Ghana mandates that the spouse, in this stance, be the wife to cater to the welfare and health of their husband. Failure to carry out such responsibilities is seen as culturally unacceptable and comes with vilification and curses from the in-laws of the care recipient. A female caregiver (Tribe-Dagaaba) rendering care to her husband said the decision to assume the caregiving role of her husband diagnosed with ESLD was hers but not emanating from any other person since her culture would not forgive her if she reneged that duty.

> It was not the family's decision that I should be the one taking care of the patient but my personal decision. What will my in-laws say about me if I fail to care for their son whom I am married to? Even culturally it is not right for me to abandon my sick husband's care needs to a different person. I can't even stand the insults and curses should he die as a result, and I attend the funeral rites. (**FC14**)

In furtherance, family cohesion was yet another factor. Participants intimated that as a family unit, they supported each other when they were all in good health, and therefore, providing care for a sick relative is part of the support that exists in the family.

> …as a family, the health of each member is important to everyone, we supported each other when we were all healthy so now that my brother is feeling unwell, I must assist him the best I can so that he will recover and join the rest of the family. I took up the responsibility of caring for him because he is my own and would have done the same if I were the one who fell sick. (**FC12**)

Again, the cultural orientation of Ghanaians towards the feminine gender assigns caring for sick relatives to women, specifically mothers, sisters and daughters. As a result, some female participants expressed that it was socially and culturally expected of them to care for sick family members as mothers and older daughters. A mother providing care for her daughter is illustrated in the quote below:

> My father asked me to come from Accra and take care of my auntie, so it was my father's decision for my being a family caregiver now to my auntie. My patient doesn't have female children so being a female my father called upon me to take charge of her care…as you can see, she's a female and it will be difficult for her sons to cater for her. (**FC11**)

On assuming caregiving responsibility, a brother-in-law attributed it to a good relationship as the driving force. He stated that he had a good bond with his sister, who, at the time of the husband's sickness, was nursing a 1 month-old baby, which he said health-wise was not appropriate to be at the hospital. He recounted that to care for his brother-in-law, he was forced to put up with being apart from his wife and kids. The case below highlights this understanding:

> I took up the caregiving role first because my brother-in-law and I have a cordial relationship, so when my sister told me about the situation I had to step in and assist. My sister just delivered, and it is not advisable to bring this child to the hospital at this tender age. It wasn't an easy decision, but my sister and I are always there for each other, so I am here and ok with the decision. (**FC9**)

Reciprocity

Reciprocity was a key motivator for many FCs, driven by the sense of fulfilling their familial obligation to provide care. Participants viewed caregiving as an opportunity to repay their loved ones for the sacrifices and support, such as upbringing, payment of school fees and provision of needs, received throughout their lives.

> …. father and son are one, I feel that once he brought me to this world and took care of me up to this stage, whether I was prepared for the role or not I think this is the little I can also do to appreciate all he has done for me. (**FC10**)

Some participants who had a parental relationship with the care recipient cited that they did not know how dependent they were on the care receiver in their growing years. They, therefore, feel obliged to reciprocate all the efforts and resources the care recipient committed to their upbringing. This is shown in the following narratives:

> … being a family caregiver for my father is not a problem for me at all because when I was young, I did not know what happened in terms of the care my father provided to me. I feel it is time I also reciprocate what he did for me. So, I am ready to do anything within my capability to help him regain his health. (**FC15**)

> What motivates me to do what I am doing is that he has been taking care of me when I was going to school so without him, I cannot survive, and he too cannot do anything now; that is what made me take care of him. (**FC7**)

Religious obligation

Under this sub-theme, some participants viewed their caregiving duty as a religious obligation. They drew inspiration from religious scriptures that admonish human beings to care for each other, especially in times of need. Blessings therein scriptures for those who cared for the sick were a driving force for some FCs.

> … the Holy Quran admonishes us to care for the sick, and there are blessings therein from Allah. So, I am playing this role, not for any human rewards but doing exactly what our creator requires of us to do for fellow human beings. (**FC2**)

Another FC of Christian faith stated.

> I think the blessings of God upon my life for the services I am providing to my father who is sick is worth my suffering in providing care to him…I can't give you the exact quotation from the bible, but I know it is stated in the Holy Book thus Mathew 25:36 that God will bless those who care for those in need. (**FC15**)

DISCUSSION

This study sought to explore the caregiving burdens of individuals supporting patients with ESLD and the motivations that drive them on. The key findings identified cut across multiple burden domains, including financial strain, physical exhaustion, social isolation and psychological stress. Family obligation, reciprocity and religiosity were important motivators in the caregiving trajectory.

The burdens for FCs are the demands and tasks associated with providing daily care. Consistent with a study by Green *et al*,[19] caregiving causes stress because the responsibilities compete with the carer's resources and can potentially compromise the caregiver's well-being. Informal caregivers continue to experience adverse impacts of caregiving across psychological, physical and social well-being, and the terminal stage of the disease's impact on their well-being is no exception.[20 21] Similar to a study by Abreu *et al* (2020), providing care can negatively impact caregivers' physical and psychological health. Therefore, there is a need to provide guidelines and resources to support FCs assisting their loved ones living with ESLD.

FCs interviewed reported a decline in physical health because of their caregiving duties. This finding supports previous research that stressed how caregivers reported a moderate to severe decline in physical health.[22–24] Similarly, participants reported that altered sleeping patterns due to early awakening, psychological trauma, frequent sleep interruptions by clinicians and lack of sleeping facilities negatively impacted their physical health.

We identified that FCs of patients with ESLD faced considerable physical and emotional burdens resulting from the extensive demands of caregiving. Caregivers frequently experienced fatigue while managing care recipients who were incapacitated due to symptoms like ascites, weakness and encephalopathy, which hindered their ability to perform ADLs. In resource-limited settings such as Ghana, where professional palliative care is limited, caregivers frequently assume hands-on responsibilities typically managed by healthcare providers in Western contexts.[25 26] Caregiving responsibilities often resulted in health issues for participants, such as generalised body pain, sleep disturbances, physical deterioration and increased vulnerability to infections, including malaria. The findings align with those of Hudson *et al*,[27] who identified comparable challenges, including fatigue, back injuries, insomnia and caregivers' difficulties prioritising their health amid competing responsibilities.

We also identified that FCs of patients with ESLD faced considerable financial challenges stemming from the substantial treatment costs, restricted NHIS coverage and supplementary expenses for non-medical necessities, including food, diapers and transportation. Caregivers indicated their inability to partake in income-generating activities, and competing financial obligations exacerbated their economic hardship. The chronic and progressive characteristics of ESLD frequently result in patients becoming financially reliant on their caregivers, thereby increasing the burden. Some participants sold personal belongings or depleted their savings to fulfil caregiving demands, consistent with previous research indicating that caregivers experience heightened financial stress, job loss and reduced productivity.[19 28 29] This finding highlights the need for healthcare policymakers to expand the National Health Insurance Scheme to fully cover treatment costs for ESLD, as the current limited coverage presents a significant challenge. This aims to alleviate the financial burden on the patient and the FC.

Further, FCs reported suffering psychological burdens when providing care to the recipient. The psychological burden was the second most stressful factor that confronted them in their caregiving role. Participants expressed concern about the sense of impending death of the care recipient and the stigma attached to patients with ascites. This finding is in line with most previous studies on caregivers that found psychological burden as the most common stressor caregivers' encounter.[26 30 31] Similarly, a study by Khanjari *et al*[23] found that 6 months after taking on the role of caretaker, more than 70% of FCs reported suffering from severe psychological effects. Our participants mentioned chronicity of ESLD, long caregiving duration,[32] deterioration in the health status of the care recipient,[30] lack of money,[30 32–34] lack of family support and fear of impending death as significant causes of their psychological strain. These findings highlight how crucial it is for healthcare policymakers to implement caregiver-centred mental health interventions such as counselling and support groups as a top priority to enhance the psychological well-being of FCs.

In addition to the psychological burden, the FCs expressed that their caregiving responsibilities adversely affected their social lives. Participants highlighted that their engagement in caregiving activities limited their participation in social events, attributing this social burden to the significant time spent providing daily care and taking on most day-to-day responsibilities for their care recipient. In northern Ghana, social events such as weddings, baby-naming ceremonies and funerals are vital for fostering unity and a sense of belonging, making attendance important.[35] The study's results align with prior research, confirming that caregivers' time for socialising or being with friends is constrained by their caregiving obligations.[36–39] Notably, younger caregivers in this study expressed greater dissatisfaction with the negative impact of caregiving on their social lives, a sentiment expected given their generally higher enthusiasm for participating in social events compared with older caregivers.

The study further identified motivation as a key resource in this burdensome caregiving role, especially in ESLD. Some FCs were intrinsically motivated by empathy and affection, while others were externally driven by parental obligation, reciprocity and socio-cultural responsibilities. The finding of this study elicits that the caregiver's motivation for providing care was primarily underpinned by three key factors: socio-cultural factors, reciprocity and religiosity. Many of the reasons cited were based on enduring family ties, strong feelings like love and a desire to repay or return care the patient had previously provided with ESLD.

The study highlights the pervasive cultural norm in Ghana, where the family is viewed as the primary support system for individuals facing terminal illnesses like ESLD. Socio-cultural obligations, including familism, filial piety and cultural duty, emerged as significant motivators for individuals assuming caregiving roles.[40–42] This study revealed that in Ghanaian society, caregiving is considered an unspoken family value and a moral duty, leading adult children to feel compelled to provide care for their terminally ill relatives. Participants expressed that those socio-cultural obligations played a crucial role in influencing them to take on the responsibility of caring for patients with ESLD. This study is consistent with studies by Kristanti *et al*,[43] Ng *et al*,[44] Segrin *et al*[45] and Yeung *et al*,[46] which highlighted the influence of cultural values and social norms on carers' decisions to take on caregiving responsibilities. Filial piety was highlighted as a cultural norm shaping personal expectations for adult children to provide parental care.

Additionally, familism was implicitly expressed, emphasising that the family should exclusively care for an ill family member. Caregivers view their roles as a mark of loyalty and pride, considering abandoning a relative in ill health is culturally unacceptable.[9] This study supports the idea that caregiving is a shared family activity influenced by important cultural values.[46]

Reciprocity emerges as a significant motivator for caregivers, with most participants citing it as a crucial factor in taking on the caregiving role. The obligation to reciprocate love and care to the care recipient is emphasised, grounded in the cultural expectation that those who have received care in the past should provide similar care when someone falls sick. Participants view reciprocating good deeds as a cultural norm, making the care recipient's previous conduct towards family or community members a precondition for receiving informal care. This aligns with a study by Zarzycki *et al*,[47] which found a link between receiving care in rural Ghana and earlier good deeds by the care recipient. Similarly, Kusi *et al*[26] observed caregiving as a way of repaying past favours.

According to participants in this study, religiosity, which constitutes religious beliefs and values, was an important motivating factor initiating and sustaining caregivers' motivation for caregiving. Participants stated that religious or spiritual teaching influenced their decision to take up caregiving duties. Several studies corroborate this finding.[48–51] Participants' belief in the care recipient's illness as having arisen from the will of God was a significant motivation to continue to render care to their family members. This finding validates research by Alonso *et al*[48] in which caregivers indicated that believing in God's presence in every situation encouraged them to continue providing care. Future studies could examine how religion manifests in caregiver and care-recipient relationships and fosters caregiver resilience.

The findings of this study should be viewed in light of some few limitations. The retrospective interviews may have introduced recall bias, which could lead to an overrepresentation of FCs experiencing more significant burdens and lower quality of life. Also, the study's findings cannot be generalised due to socio-economic and cultural differences in Ghana, as participants were selected from the northern region.

CONCLUSION

Family caregiving is a complex phenomenon characterised by a delicate balance between a heavy responsibility burden and a deep motivation to care for a loved one. As caregivers navigate the caregiving process, they are faced with myriad challenges, such as physical exhaustion, susceptibility to infections, financial strains, psychological distress and social isolation. Bolstering motivation factors such as socio-cultural obligations, reciprocity and religious duty was crucial in promoting the resilience and well-being of the caregiver. By understanding the factors contributing to caregiver burden and motivating factors, healthcare providers and policymakers in health can work towards implementing targeted interventions to support this vulnerable group.

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REFERENCES

1 Huang J, Lok V, Ngai CH, *et al*. Disease Burden, Risk Factors, and Recent Trends of Liver Cancer: A Global Country-Level Analysis. *Liver Cancer* 2021;10:330–45.
2 Woodrell CD, Mitra A, Hamilton A, *et al*. Burden, Quality of Life, and Palliative Care for Family Caregivers of Individuals with Advanced Liver Disease: a Systematic Literature Review. *Curr Hepatology Rep* 2021;20:198–212.
3 Sharma A, Nagalli S. Chronic liver disease. 2021. Available: https://www.ncbi.nlm.nih.gov/books/NBK554597/
4 Hansen L, Lyons KS, Dieckmann NF, *et al*. Background and design of the symptom burden in end-stage liver disease patient-caregiver dyad study. *Res Nurs Health* 2017;40:398–413.
5 Adjei CA, Atibila F, Apiribu F, *et al*. Hepatitis B Infection among Parturient Women in Peri-Urban Ghana. *Am J Trop Med Hyg* 2018;99:1469–74.
6 Amponsah-Dacosta E. Hepatitis B virus infection and hepatocellular carcinoma in sub-Saharan Africa: Implications for elimination of viral hepatitis by 2030? *World J Gastroenterol* 2021;27:6025–38.
7 Nartey YA, Awuku YA, Agyei-Nkansah A, *et al*. Ambulatory end-stage liver disease in Ghana; patient profile and utility of alpha fetoprotein and aspartate aminotransferase: platelet ratio index. *BMC Gastroenterol* 2020;20:428.
8 Kedar Mukthinuthalapati VVP, Sewram V, Ndlovu N, *et al*. Hepatocellular Carcinoma in Sub-Saharan Africa. *JCO Glob Oncol* 2021;7:756–66.
9 Salifu Y, Almack K, Caswell G. "My wife is my doctor at home": A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting. *Palliat Med* 2021;35:97–108.
10 Yanny B, Pham NV, Saleh H, *et al*. Approaches to Assessing Burden in Caregivers of Patients with Cirrhosis. *J Clin Transl Hepatol* 2020;8:127–34.
11 Choi S, Seo J. Analysis of caregiver burden in palliative care: An integrated review. *Nurs Forum* 2019;54:280–90.
12 Wong DFK, Lam AYK, Chan SK, *et al*. Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: roles of caregiver characteristics, caregiving burdens, and satisfaction with psychiatric services. *Health Qual Life Outcomes* 2012;10:15.
13 Sanuade OA, Boatemaa S. Caregiver profiles and determinants of caregiving burden in Ghana. *Public Health (Fairfax)* 2015;129:941–7.
14 Yakubu YA, Schutte DW. Caregiver attributes and socio-demographic determinants of caregiving burden in selected low-income communities in cape town, South Africa. *J of Compassionate Health Care* 2018;5.
15 Etikan I, Musa SA, Alkassim RS. Comparison of Convenience Sampling and Purposive Sampling. *AJTAS* 2016;5:1.
16 Creswell JW. *Research Designs. Qualitative, Quantitative, and Mixed Methods Approaches*; SAGE Publications; 2014.
17 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
18 Lincoln YS, Guba EE. RESEARCH, EVALUATION, AND POLICY ANALYSIS: HEURISTICS FOR DISCIPLINED INQUIRY. *Review of Policy Research* 1986;5:546–65.

19 Greene J, Cohen D, Siskowski C, *et al*. The Relationship Between Family Caregiving and the Mental Health of Emerging Young Adult Caregivers. *J Behav Health Serv Res* 2017;44:551–63.

20 Stajduhar KI. Burdens of family caregiving at the end of life. *Clin Invest Med* 2013;36:E121–6.

21 Williams AM, Wang L, Kitchen P. Impacts of care-giving and sources of support: a comparison of end-of-life and non-end-of-life caregivers in Canada. *Health Soc Care Community* 2016;24:214–24.

22 Hashemi-Ghasemabadi M, Taleghani F, Yousefy A, *et al*. Transition to the new role of caregiving for families of patients with breast cancer: a qualitative descriptive exploratory study. *Support Care Cancer* 2016;24:1269–76.

23 Khanjari S, Langius-Eklöf A, Oskouie F, *et al*. Family caregivers of women with breast cancer in Iran report high psychological impact six months after diagnosis. *Eur J Oncol Nurs* 2014;18:630–5.

24 Wulandari SK, Hermayanti Y, Yamin A, *et al*. Family Process with Breast Cancer Patient in Indonesia. *J Ners* 2017;12:180–8.

25 Clark D, Baur N, Clelland D, *et al*. Mapping Levels of Palliative Care Development in 198 Countries: The Situation in 2017. *J Pain Symptom Manage* 2020;59:794–807.

26 Kusi G, Boamah Mensah AB, Boamah Mensah K, *et al*. Caregiving motivations and experiences among family caregivers of patients living with advanced breast cancer in Ghana. *PLoS ONE* 2020;15:e0229683.

27 Hudson B, Hunt V, Waylen A, *et al*. The incompatibility of healthcare services and end-of-life needs in advanced liver disease: A qualitative interview study of patients and bereaved carers. *Palliat Med* 2018;32:908–18.

28 Cohen E, Benvenisti Y. Public policy for supporting employed family caregivers of the elderly: the Israeli case. *Israel Affairs* 2020;26:431–49.

29 Fricker ZP, Serper M. Current Knowledge, Barriers to Implementation, and Future Directions in Palliative Care for End-Stage Liver Disease. *Liver Transpl* 2019;25:787–96.

30 Sahadevan S, Namboodiri V. Depression in caregivers of patients with breast cancer: A cross-sectional study from a cancer research center in South India. *Indian J Psychiatry* 2019;61:277–82.

31 Yeung NCY, Zhang Y, Ji L, *et al*. Guilt among husband caregivers of Chinese women with breast cancer: The roles of male gender-role norm, caregiving burden and coping processes. *Eur J Cancer Care* 2018;27:e12872.

32 Selamat Din SH, Nik Jaafar NR, Zakaria H, *et al*. Anxiety Disorders in Family Caregivers of Breast Cancer Patients Receiving Oncologic Treatment in Malaysia. *Asian Pac J Cancer Prev* 2017;18:465–71.

33 Moreno-González MM, Galarza-Tejada DM, Tejada-Tayabas LM. Experiences of family care during breast cancer: the perspective of caregivers. *Rev Esc Enferm USP* 2019;53.

34 Nik Jaafar NR, Selamat Din SH, Mohamed Saini S, *et al*. Clinical depression while caring for loved ones with breast cancer. *Compr Psychiatry* 2014;55 Suppl 1:S52–9.

35 Yirenkyi SM. Ritual Performative Ceremonies and Values in the African Context. *International Journal of African and Asian Studies* 2019;57.

36 Arian M, Younesi SJ, Khanjani MS. Explaining the Experiences and Consequences of Care Among Family Caregivers of Patients with Cancer in the Terminal Phase: A Qualitative Research. *Int J Cancer Manag* 2017;10.

37 Jeppesen PB, Chen K, Murphy R, *et al*. Impact on caregivers of adult patients receiving parenteral support for short-bowel syndrome with intestinal failure: A multinational, cross-sectional survey. *JPEN J Parenter Enteral Nutr* 2022;46:905–14.

38 Rokicka M, Zajkowska O. Informal Elderly Caregiving and Time Spent on Leisure: Evidence from Time Use Survey. *Ageing Int* 2020;45:393–410.

39 Silvestro D, Azicnuda E, DIppolito M. Beyond the Classical Psychotherapeutic Setting to Better Provide Support for Caregivers of Persons with Severe Acquired Brain Injury: Some Clinical Evidence. *J Psychol Psychother* 2016;06:6–9.

40 Dunér A. Motives, experiences and strategies of next of kin helping older relatives in the Swedish welfare context: a qualitative study. *Int J Soc Welfare* 2010;19:54–62.

41 Parveen S, Morrison V, Robinson CA. Ethnicity, familism and willingness to care: Important influences on caregiver mood? *Aging Ment Health* 2013;17:115–24.

42 Qadir F, Gulzar W, Haqqani S, *et al*. A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. *Care Manag J* 2013;14:230–40.

43 Kristanti MS, Effendy C, Utarini A, *et al*. The experience of family caregivers of patients with cancer in an Asian country: A grounded theory approach. *Palliat Med* 2019;33:676–84.

44 Ng HY, Griva K, Lim HA, *et al*. The burden of filial piety: A qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. *Psychol Health* 2016;31:1293–310.

45 Segrin C, Badger TA, Sikorskii A. A dyadic analysis of loneliness and health-related quality of life in Latinas with breast cancer and their informal caregivers. *J Psychosoc Oncol* 2019;37:213–27.

46 Yeung NCY, Zhang Y, Ji L, *et al*. Correlates of sexual quality of life among husbands of Chinese breast cancer survivors. *Eur J Oncol Nurs* 2019;40:63–70.

47 Zarzycki M, Seddon D, Bei E, *et al*. How Culture Shapes Informal Caregiver Motivations: A Meta-Ethnographic Review. *Qual Health Res* 2022;32:1574–89.

48 Alonso WW, Kitko LA, Hupcey JE. Intergenerational Caregivers of Parents With End-Stage Heart Failure. *Res Theory Nurs Pract* 2018;32:413–35.

49 Arpanantikul M. Women's perspectives on home-based care for family members with chronic illness: An Interpretive phenomenology study. *Nurs Health Sci* 2018;20:494–501.

50 van Wezel N, Francke AL, Kayan-Acun E, *et al*. Family care for immigrants with dementia: The perspectives of female family carers living in The Netherlands. *Dementia (London)* 2016;15:69–84.

51 Zhang J, Lee DTF. Meaning in Stroke Family Caregiving in China: A Phenomenological Study. *J Fam Nurs* 2019;25:260–86.