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# Unseen burden: Exploring caregiver experiences, barriers, and facilitators in foregut cancer care

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## Abstract

**Introduction:** Caregivers play a pivotal role in supporting foregut cancer patients, yet their experiences and the challenges they face are overlooked. Understanding caregivers' experiences and the barriers and facilitators they encounter can inform interventions to improve their well-being and, ultimately, patient outcomes. This study focuses on the lived experiences and the interpersonal factors that shape the caregivers' journeys.

**Methods:** Semi-structured interviews were conducted with caregivers of patients with foregut cancer receiving treatment at a safety-net hospital in the Deep South. Interviews were recorded, transcribed and qualitatively analyzed using NVivo 14 software. Grounded theory methodology was used to guide analysis. Three co-authors independently coded the data, with intercoder agreement of above 90 %.

**Results:** Of the 15 caregivers interviewed, the majority were female, spouses of the patients, and resided in areas of high socioeconomic deprivation. Three theme categories emerged: caregiver experiences, individual/interpersonal level barriers, and individual/interpersonal level facilitators. Caregivers expressed self-sacrifice and a strong sense of duty, describing caregiving as a priority despite personal hardships. Barriers included psychological distress, financial strain, competing responsibilities, transportation challenges, social isolation, and patient denial. Conversely, facilitators included support from family and friends, religious and spiritual practices, and engagement in support groups.

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Ethics Statement
None

**Conclusion:** Caregivers of patients with foregut cancer face significant psychological and financial burden, compounded by competing responsibilities and limited social support. Interventions aimed at reducing caregiver burden and enhancing support mechanisms will improve both caregiver well-being and patient outcomes. Future research should focus on strategies that promote these facilitators and address barriers to caregiving.

**Keywords**

Foregut Cancer; Caregivers; Social Determinants of Health; Qualitative; South

## Introduction

Caregivers play an essential yet underappreciated role in supporting patients with foregut cancer (i.e., cancers of the pancreas, hepatobiliary system, esophagus and stomach), malignancies with poor prognoses and complex treatment regimens.[1] The demands of caregiving extend beyond logistical coordination of medical appointments, to include navigation of financial and bureaucratic healthcare system challenges, and provision of emotional and psychological support.[2] The overall burden of caregiving can lead to increased psychological distress, social isolation, and a decline in the caregivers' quality of life.[3] Given the poor prognoses associated with foregut cancers and the intensive-multimodal treatment regimens required for their management,[4] understanding caregivers' experiences is essential for developing supportive interventions that can enhance caregiver well-being and patient outcomes.

Disparities in cancer care and outcomes are well established, particularly in the Deep South, where socioeconomic deprivation and limited healthcare access contribute to worse outcomes among patients with foregut cancer. Caregivers in this context are likely to face unique challenges. While prior studies have evaluated caregiver burden and quality of life, there remains a notable gap in qualitative research specifically focusing on the perspectives and lived experiences of caregivers for patients with foregut cancer in minoritized populations in the Deep South.[5]

This study aims to address this gap by exploring the experiences of caregivers for patients with foregut cancer treated at a safety-net hospital in the Deep South, and the individual- and interpersonal- level barriers and facilitators they encounter. This study provides novel insights into the factors that shape the caregiving journey by centering the voices of caregivers in the context of a highly deprived and minoritized setting.[5,6] Understanding these experiences can inform the development of interventions to mitigate caregiver burden, enhance support and improve quality of life for both caregivers and patients.

## Methods

### Study design and participant recruitment

This qualitative study employed a grounded theory approach to explore the experiences of caregivers of patients with foregut cancer. Grounded theory was selected to allow for an inductive, data-driven exploration of caregiving experiences, emphasizing how caregivers navigate their roles and the barriers and facilitators they encounter.

English-speaking, adult caregivers of patients with esophageal, gastric, pancreatic, or hepatobiliary cancer receiving treatment at a safety-net and tertiary facility in the Deep South between May 2022 and May 2023 were invited to participate. Participants were purposively sampled based upon a combination of factors including type of cancer, self-reported barriers to care and geographic location. Participants were recruited in clinic by a member of the research team not involved in clinical care, and participated in in-person, semi-structured interviews that lasted 30–60 minutes. The study protocols and all associated materials were approved by the University of South Alabama (USA) Institutional Review Board (IRB-2003085–1).

## Participant interviews

The semi-structured interview guide was developed based on grounded theory methodology to capture caregivers' experiences and perspectives.[7] The interview guide was pilot tested with two caregivers prior to the start of formal data collection to assess clarity and ensure appropriateness and relevance of questions. Open-ended questions and probing responses were included to encourage dialogue. The interview guide is included as Supplementary 1. All study participants provided informed consent for the interviews and received a financial incentive of $25 for their participation. The two interviewers were female graduate students who had been trained in semi-structured interviewing by a clinical psychologist and an experienced member of the research team. Interview recordings and field notes were made during the interviews and were reviewed throughout the study to mitigate interview drift and ensure accuracy. Repeat interviews were not deemed necessary, and caregivers did not receive a transcript of their interview or provide feedback on the results of the study. Interviews continued until thematic saturation was achieved.

## Background sociodemographic characteristics

Age, gender, race, relationship to the patient, and patient insurance status were recorded. Neighborhood disadvantage was also assessed for each participant based on the Area Deprivation index (ADI) by geocoding addresses and using the ADI mapping atlas.[8] This is a validated neighborhood-level composite score level that incorporates multiple socioeconomic variables under the domains of income, education, employment, and housing quality, and is designed to assess neighborhood disadvantage at the census block group level.[6] The state ADI ranges from 1 to 10 and is a decile ranking, with increasing scores corresponding to higher area deprivation. For this study, it was categorized into terciles; low (1–3), intermediate (4–6), and high (≥7) deprivation, as previously described.[9]

## Qualitative data

All interviews were audio-recorded, transcribed and verified for accuracy. Transcripts were independently analyzed by two coders (MH, IH) using the NVivo 14 software (QSR International). Grounded theory methodology was used to guide inductive content analysis.[10] Open coding was first conducted to generate preliminary themes. Consensus coding was used to finalize themes and develop a thematic coding structure in secondary coding. The emerging themes were subsequently organized into three categories: overall caregiver experience, individual/interpersonal level barriers, and individual/interpersonal level facilitators. Through regular discussion among coders, the codebook was finalized with an intercoder agreement of above 90 %.

## Results

### Background Characteristics

A total of 15 caregivers participated in the study. The majority were female (n = 13, 87 %), and identified as Black (n = 11, 73 %). The median age was 63 years (interquartile range: 49–68). Most caregivers were spouses of the patient (n = 10, 67 %), while 20 % (n = 3) were children and 13 % (n = 2) were parents. Notably, 73 % (n = 11) of caregivers resided in areas of high socioeconomic deprivation (high ADI). Patient insurance coverage varied, with 27 % (n = 4) having private insurance, 33 % (n = 5) relying on Medicare, 33 % (n = 5) on Medicaid, and 6.7 % (n = 1) was uninsured.

### Overall caregiver experience

A summary of the themes and quotes is presented in Table 1. Self-sacrifice and feeling of duty emerged as a major theme, with many describing caregiving as their primary responsibility, often prioritizing patient needs over their own. As one caregiver reflected, “I have dedicated myself to whatever she needs… I had to stop working. So financially it has been hard. But this is a blessing to be able to spend this much time with her, It’s not about me. My mother has cancer. It’s about her.”. Another shared, “He took care of me for 40 years… I’ll always be there for him”. Caregivers often expressed a deep sense of obligation and a feeling there was no choice but to persevere, even at the cost of their own wellbeing, with one mentioning: “You can’t give up because your husband or wife needs you. You are all they have so you have to be there for them”. Others described their resilience in the face of hardship, with one caregiver stating, “You just have to stand and hold on…You don’t get to think about yourself. Because your husband or your wife has cancer. So you have to be there for them”.

### Individual and interpersonal barriers

Nearly all caregivers reported significant emotional burden, with anxiety, depression and feelings of helplessness being common. As one caregiver shared, “When she’s sick you watch her and there’s nothing you can physically do, and that’s rough on somebody”. Financial strain was reported by over half of the caregivers, with one of them reflecting: “Treatment is important so everything else takes a back seat. Bills, food, all of the other things. You do the best you can and hope it’s enough”. Competing responsibilities, such as managing other dependents and household tasks, further added to caregivers’ burden with half of caregivers underscoring this as a barrier. A caregiver explained, “We have two grand babies that we have custody of… I have to see about him (patient), get the babies ready for school… I do everything”. Transportation challenges were also frequently reported by caregivers, both due to the cost and logistics of transport. As one noted, “We have to come up with the money to pay for gas…That is one of the reasons transportation is difficult”. Health limitations of caregivers also hindered transportation with one caregiver stating, “I have arthritis myself, and I have a lung disease… I might get out of air before I get where I need to be, but sometimes I just go”.

Social isolation and lack of support were reported by some caregivers, with one stating “Nobody. I do it. It’s me. It’s me, him and the babies. I don’ have any help. I don’ have anybody helping me. I do it….I do everything.”. While less frequently reported, patient denial was also described by some caregivers, who reported struggles with patients not acknowledging their illness or limitations imposed on them by their illness, with one participant reflecting “If he would just accept where he’s at and take it a day at a time instead of, “Oh, I’ve got to get back to work and go a million miles an hour”, because his body’s just not there yet.”.

### Individual and interpersonal facilitators

Despite the challenges, caregivers identified several key individual and interpersonal facilitators that supported them. Most caregivers relied on their families for emotional, logistical, and financial support. A caregiver explained, “My children, my sister… We have a good supporting system, even though they are far, but they are here when we need them”. Over half the participating caregivers relied on faith-based support networks, predominantly their church communities, for emotional support. As one caregiver emphasized, “…we got prayer warriors, and they pray for him, and they pray for me, and I got much stronger than what it was”. Some caregivers sought support from peer support groups, finding value in shared experiences and practical advice from others who were currently navigating or had navigated similar challenges. One caregiver reflected “Maybe they (people in the support group) can tell me something that I don’t know that can help him be more comfortable”.

## Discussion

With more than 3 million people in the US actively caring for a patient with cancer in their close social circle, and the incidence of foregut cancers rising, the importance of the informal caregivers’ role becomes even more prominent.[1,11,12] Despite this crucial role, their experiences and perspectives are often overlooked. This study, conducted at a safety-net hospital in the Deep South, highlights the profound impact of caregiving and the substantial individual and interpersonal challenges faced, while also identifying key facilitators. Unlike much of the existing literature which has primarily focused on white, middle to upper income caregiver populations,[13] this study provides insight into the experiences of caregivers in a predominantly Black and socioeconomically disadvantaged population. The structural inequities experienced by this population exacerbate caregiver burden, making our findings particularly relevant for improving caregiver support in underserved communities.[14] Moreover, the study’s setting in a safety-net hospital provides valuable insights into the unique challenges faced by caregivers in resource-limited health system environments. Additionally, while prior studies have examined caregiver burden more broadly, few have specifically explored their self-reported experiences along with individual- and interpersonal- level facilitators that may be leveraged to improve caregiver well-being. Consistent with the literature, most caregivers in this study were female, reflecting a broader trend where women predominantly assume this role[1,15]

Caregivers in this study frequently expressed a profound sense of duty, often prioritizing the needs of the patient over their own well-being. The psychological toll was striking, with most participants reporting significant emotional distress. This aligns with prior research which describes the caregivers prioritizing the patient's well-being over their own,[16] and this has been demonstrated to impact their quality of life, often leading to secondary mental or physical disease.[17] Treating caregivers as integral members of the cancer care team, and integrating caregiver support into standard oncology care, would help to address these challenges.[18] Proactive assessment of caregiver burden at regular intervals using validated screening tools, such as the Caregiver strain index,[19] or the Zarit burden interview,[20] followed by the initiation of supportive interventions for caregivers at high risk for distress, may help mitigate some of the mental burden.

The barriers reported by caregivers at the individual and interpersonal levels are significant and multifaceted. The most common concerns highlighted in this study were psychological distress, financial strain, competing responsibilities, and transportation challenges. These barriers are consistent with the literature, where caregivers often report feeling overwhelmed by their responsibilities and a lack of adequate support systems.[21,22]

The degree of psychological distress observed in our study closely corresponds with that reported in the literature. In their cross-sectional study that evaluated distress among caregivers of patients with cancer based on quantitative metrics, Kirk et al., found that more than 90 % of the caregivers experienced substantial mental distress.[23] Severe, clinically significant distress among caregivers has been reported with varying prevalence – 30–70 % – across the literature.[3,23] The almost universal reporting of significant emotional distress by caregivers in this study is likely reflective of the impact of structural inequities experienced by caregivers in under-resourced communities who face systemic healthcare barriers and may have fewer resources and support at their disposal.[24] Recent ASCO guidelines indicate that caregivers should receive information on the psychological effect a patient's cancer diagnosis may have on them, and when appropriate, providers should arrange timely referrals to psychologists and mental health support workers.[25] The integration of mental health resources into oncology care plans is critical, particularly in safety-net hospitals which often serve populations with high unmet mental health needs.[26] The establishment of structured interventions such as caregiver stress-management workshops[27] or mindfulness-based coping strategies,[28] as well as streamlined referral pathways for caregivers to access therapy, support groups, or pharmacological interventions may mitigate psychological distress. A multimodal and adaptable approach, which is customized to each caregiver's unique experience, may lead to improved mental health outcomes for caregivers and patients by proxy.[15,29] Importantly, caregivers should be actively included in the shared decision-making process as many aspects of their life are directly affected by both the diagnosis and its consequences.[1] In their landmark systematic review, Wang and colleagues highlighted that caregivers' informational needs were their largest unmet need, and thus ways to improve caregiver-provider communication should be further studied.[30]

Financial strain is a major concern in foregut cancer treatment. Caregivers of patients with cancer often lose their ability to work or have to reduce their work hours. This, along with out-of-pocket medical expenses and costs associated with transportation, result in significant financial hardship.[31] While patient financial assistance programs exist, caregivers do not usually qualify for financial support to offset the negative economic consequences of caregiving. Financial navigators within cancer centers should proactively assist caregivers in identifying resources including access to transportation services, utilities and other financial assistance programs, to alleviate the burden on caregivers.[32] Given that many caregivers rely on faith-based or community networks for support, health system collaboration with local religious organizations may help expand the pool of resources available to caregivers.[33,34] At the policy level, paid family leave and greater flexibility in work schedules would give caregivers the necessary assistance to carry out their crucial responsibilities.[1,35]

Transportation challenges were also frequently cited as a barrier. Intervention strategies to facilitate transportation access could include the development of partnerships with rideshare companies and community-based transportation programs, as well as health system funded shuttle services.[36,37] Telehealth can also play a critical role in mitigating transportation burden, and may ensure continued access, particularly for follow-up visits, and could be used to facilitate caregiver support consultations.[38] The provision of services such as digital literacy training and technical assistance provision could help patients and caregivers' access to telehealth services more efficiently.[39]

Support from family and friends emerged as a crucial facilitator for caregivers. Religious community and spiritual practices were also significant facilitators. The important role of the church and church community has been reported by other studies in the Southern USA.[34] Current research shows that particularly in communities of color, religion and spirituality can equip both caregivers and patients with coping mechanisms to navigate cancer care while also offering more tangible support related to their care.[40] The strong role of family and community support suggests that health systems should facilitate more opportunities for peer connection. Structured caregiver mentorship programs, or caregiver support groups where caregivers can obtain formal or informal advice and guidance, may help alleviate some of the anxiety associated with their role.[41] Additionally, navigators embedded within oncology clinics may not only serve as a bridge between the health system, providing support, but may also aid in connecting caregivers with community-based organizations that provide meal delivery, respite care or in-home assistance, while mobilizing the caregiver's current social support system.[42,43] While not explicitly mentioned by our study participants, caregiving has also been described as rewarding; providing individuals with satisfaction and purpose.[31] Therefore, aside from addressing the barriers, it is vital to promote these facilitators that caregivers have identified.

While this study provides valuable insights, several limitations should be acknowledged. The small sample size of caregivers limits its generalizability. While our study setting provides crucial insight into the perspectives of an underserved caregiver population, these findings may not reflect the experiences of caregivers in other regions or socioeconomic contexts. The percentages of caregivers reflecting each theme in Table 1 are provided solely to describe our participants perspectives and not for broader inferences. Additionally, this study focused primarily on individual and interpersonal barriers and facilitators and does not address structural and policy-level issues. Lastly, this study captured caregivers' experiences at a single point in time, and while we attempted to understand their experiences throughout the patients' cancer care journey, this does not provide sufficient insight into the changing needs of caregivers throughout the cancer care continuum.

In conclusion, this study underscores the significant emotional, financial and logistical burden experienced by caregivers of patients with foregut cancer in the Deep South. These findings highlight the need for systemic change in how the role of caregivers is perceived within the healthcare framework. By integrating caregiver support into standard oncology care, expanding mental health and financial resources and leveraging existing community networks, health systems and cancer care teams can alleviate some of this burden. As the oncology community moves towards more patient-centered care models, recognizing and addressing the needs of caregivers must be a priority. Future research should prioritize enhancing communication between caregivers and healthcare providers, fostering greater caregiver participation in the shared decision-making process, and addressing barriers that hinder access to necessary resources and support systems.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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## Synopsis

This study explores the experiences of caregivers of foregut cancer patients who received treatment at a safety-net hospital in the Southeast USA. Findings focus on the lived experiences of caregivers, along with barriers and facilitators in the individual-interpersonal level.

## Table 1

Caregiver Reported Experiences and Interpersonal Barriers and Facilitators.

| THEME | PERCENTAGE | REPRESENTATIVE QUOTE(S) |
|---|---|---|
| **OVERALL CAREGIVER EXPERIENCE** | | |
| **Self-sacrifice and a Strong Sense of Duty** | 60 % | “I have dedicated myself to whatever she needs is going to happen. So I don’t have any problem… I had to stop working. So financially it has been hard. But this is a blessing to be able to spend this much time with her, where I used to work every day, all day, seven days a week… It’s not about me. My mother has cancer. It’s about her. I’m fine.”<br>“Because your husband or your wife has cancer. So you have to be there for them. You are not important, they are.” |
| **INDIVIDUAL/INTERPERSONAL LEVEL BARRIERS** | | |
| **Psychological Distress** | 87 % | I’m on antidepressants now, but I take it at night. I don’t have anything for the day because all I can think about all day is my brother and my mother, and I know she’s not gonna be here. |
| **Financial Strain** | 53 % | Treatment is important so everything else takes a back seat. Bills, food, all of the other things. You do the best you can, and hope it’s enough |
| **Competing Responsibilities** | 47 % | We have two grand babies that we have custody of. So they’re in the house, they are in school. I have to see about him, get the babies ready for school, get them, do what they have to do. I do everything. |
| **Transportation Challenges** | 33 % | Like I said, I can drive, but I don’t drive very much. I need a wheelchair sometimes. I have no idea how to get from here to where we live. |
| **Social Isolation** | 20 % | Nobody. I do it. It’s me. It’s me, him and the grand babies. I don’t have any help. I don’t have anybody helping me. I do it….I do everything. |
| **Patient Denial** | 13 % | If he would just slow down and not be in such a rush, too. If he would just accept where he’s at and take it a day at a time instead of, “Oh, I’ve got to get back to work and go a million miles an hour,” because his body’s just not there yet. |
| **INDIVIDUAL/INTERPERSONAL LEVEL FACILITATORS** | | |
| **Religious and Spiritual Practices** | 53 % | …we got prayer warriors, and they pray for him, and they pray for me and I got much stronger than what it was… |
| **Support from Family and Friends** | 93 % | My children, my sister. We have a good supporting system, even though they are far, but they are here when we need them, or we FaceTime, and we have (emotional) support. |
| **Engagement in Support Groups** | 40 % | Maybe they (people in the support group) can tell me something that I don’t know that can help him be more comfortable. |