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The Impact of Cancer Disease on the Families of the Patient, A Case Study of the Pediatric Wing, Cancer Disease Hospital in Lusaka, Zambia

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Abstract

Purpose: Globally, cancer casts a heavy shadow. An estimated 12.7 million new cases are diagnosed annually, with about 7.6 million deaths attributed to the disease. Notably, low- and middle-income countries (LMICs) bear a disproportionate burden – over half of all new cases and a staggering two-thirds of cancer deaths occur in these regions. While advancements have been made, with 5-year survival rates exceeding 80%, the fight against childhood cancer continues. Many children still tragically succumb to the disease even after this initial milestone. In fact, cancer is the leading cause of death from illness in children. This research aimed to investigate the impact of cancer disease on the families of the patient, a descriptive analysis of the pediatric wing, cancer disease hospital Lusaka, Zambia.

Methodology: The study identified five major themes reflecting the impact of cancer on patients' families. Emotional burden accounted for 31%, financial strain 30%, healthcare system challenges 25%, coping mechanisms 9%, and social isolation 6%. The majority of participants were female (88%), consistent with traditional caregiving roles. Most participants came from low-to-middle-income households, underscoring financial strain as a significant caregiving challenge. Participants' ages ranged from 21 to 61 years, with the largest group (34%) being in the 36-50 age range.

Findings: These findings underscore the urgent need for comprehensive, caregiver-centric interventions that addressing both immediate caregiving needs and a broader systemic gap in healthcare and community support for the caregivers of the children suffering from cancer at Cancer Disease Hospital in Lusaka, Zambia.

Unique Contribution to Theory, Policy and Practice: By taking actionable steps, policymakers and public health practitioners can significantly improve the well-being of caregivers and the outcomes for the children they care for.

Keywords: *Cancer Disease, Pediatric, Caregiver, Oncology, Family Burden*

INTRODUCTION

Cancer is a significant public health issue globally, affecting millions of individuals and families. The World Health Organization (WHO) defines cancer as the uncontrolled growth and spread of abnormal cells in the body, which can lead to death if untreated. In 2020, there were an estimated 19.3 million new cancer cases and nearly 10 million cancer-related deaths worldwide, with projections suggesting that the global cancer burden could rise to 28.4 million by 2040 (Slone et al., 2014). Pediatric cancer, although less common than adult cancers, poses substantial challenges for families, impacting not only the child's health but also the family's emotional and economic stability (Felix, 2023). In sub-Saharan Africa, childhood cancers account for approximately 4.3% of all cancers; however, access to timely diagnosis and appropriate treatment remains limited, resulting in higher mortality rates compared to high-income countries (Walubita, 2015).

Zambia is experiencing a growing cancer burden, with the Pediatric Wing at the Cancer Disease Hospital in Lusaka serving as a critical center for pediatric cancer care in the country. Despite advancements in pediatric oncology that have improved survival rates globally, the consequences of cancer extend beyond the patient. Families of pediatric cancer patients often face significant psychosocial, emotional, and financial challenges, making it essential to understand these impacts in local contexts like Zambia (Felix, 2023).

The well-being of the family unit is vital for managing and recovering from pediatric cancer; however, families frequently endure substantial burdens while caring for a child with cancer. Research indicates that families experience financial distress due to medical expenses, loss of income, and the need for specialized care (Yan et al., 2018). Psychologically, parents of children with cancer may suffer from anxiety, depression, and emotional exhaustion, which adversely affects their overall quality of life (Slone et al., 2014). Siblings are also impacted, often experiencing emotional neglect and behavioral issues due to the family's focus on the sick child (Yan et al., 2018).

Globally, various programs and interventions have been implemented to alleviate these effects. For example, family-centered care models offering psychological support, financial assistance, and counselling services have been adopted in many high-income countries (Slone et al., 2014). In Africa, initiatives like the WHO's "Global Initiative for Childhood Cancer" aim to enhance access to diagnosis and treatment for pediatric cancer patients (Slone et al., 2014). Locally in Zambia, strides have been made through the establishment of the Cancer Disease Hospital, which provides comprehensive cancer treatment services including pediatric oncology (Yan et al., 2018). However, despite these interventions, there remains a gap in addressing the comprehensive needs of families affected by pediatric cancer, particularly regarding the social, emotional, and economic impacts they face.

Cancer remains a significant health challenge globally, with approximately 250,000 new cases diagnosed annually in children under 15 years of age. Alarmingly, only 20-30% of these patients, primarily from high-income countries, receive adequate diagnosis and treatment (Ribeiro et al.,

2008). This study stems from the researcher's observations during clinical practice at the Cancer Disease Hospital in Lusaka, Zambia, where the emotional and financial struggles faced by parents and guardians caring for their sick children became evident. Families experience a multitude of challenges as they navigate the complexities of pediatric cancer, including financial constraints, emotional turmoil, fear, anger, and grief over potential loss. Despite existing literature on these factors, the unique experiences of families dealing with pediatric cancer necessitate a deeper exploration. Understanding these impacts is crucial for developing targeted interventions and support systems tailored to assist families during this difficult time.

This study aimed at exploring and understanding the multifaceted impact of pediatric cancer on the families of patients at the Cancer Disease Hospital, including their emotional, psychological, relational, and social experiences.

METHODOLOGY

Study Design

This study was a descriptive qualitative study aimed at exploring the impact of pediatric cancer on the families of patients receiving treatment at the Cancer Diseases Hospital (CDH). The study used a phenomenological approach, focusing on understanding the lived experiences of families dealing with pediatric cancer. This approach is appropriate for capturing the emotional, social, and financial burdens faced by these families in a naturalistic setting. Qualitative studies allow for the in-depth exploration of complex phenomena, especially in healthcare, where patient and family experiences are deeply personal (Creswell, 2014). A phenomenological study enables participants to share their lived experiences in their own words, providing insights that are rich and meaningful (Smith, 2011).

Study Site

The study was conducted at the Cancer Diseases Hospital (CDH), located in Lusaka, the capital city of Zambia. CDH is the country's only specialized cancer treatment facility, serving patients from across Zambia and neighboring countries. The hospital has a capacity of 252 beds and includes a pediatric wing that provides specialized cancer treatment to children. Lusaka is an urban area with diverse socio-economic characteristics, including both low-income and middle-income populations, which reflect the varied economic challenges families face when dealing with chronic illnesses like cancer (World Bank, 2021). The decision to conduct the study at CDH is based on its central role in pediatric cancer care and its significance as a referral center for Zambian and regional patients, making it an ideal site for understanding the impact of pediatric cancer on families.

Study Population

The study population consists of parents and guardians of children admitted to the pediatric wing at CDH. These individuals are typically the primary caregivers and are directly affected by the emotional, financial, and social burdens of caring for a child with cancer. The study will focus on

this population as they are central to understanding the impact of the disease on the family unit. The study population will be further defined by demographic characteristics such as age, gender, socio-economic status, and residential location, as these factors may influence the extent of the impact on families.

Sample Size/Participants

The study included a sample of 50 participants, consisting of parents and guardians of pediatric cancer patients. This sample size is sufficient to achieve data saturation, a point in qualitative research where no new themes emerge from additional interviews (Guest, Bunce, & Johnson, 2006). Participants were chosen because they are directly involved in the care of the child, making them best suited to provide insights into the challenges and burdens associated with pediatric cancer. The selection criteria will ensure a diverse range of participants in terms of socio-economic background and caregiving roles, allowing for a comprehensive exploration of the research question.

Sampling of Participants

A purposive sampling method was utilized to select participants from the pediatric wing at CDH. This approach ensured that participants are deliberately chosen based on their relevance to the research objectives of caregivers of children undergoing cancer treatment. This method is effective in minimizing selection bias by ensuring that every eligible parent or guardian has the potential to be included. Although the text refers to random sampling, purposive sampling is better suited to this study's objectives because it allows for a more focused understanding of the unique burdens faced by this specific group (Bryman, 2012). By targeting caregivers dealing with pediatric cancer, the study aims to provide a more detailed and accurate representation of their challenges, rather than generalizing the findings to a broader population.

Data Collection Method and Instruments

Data was collected through one-on-one semi-structured interviews. This method is ideal for qualitative research as it allows participants to share their experiences in depth while providing flexibility for the researcher to explore specific themes as they arise during the conversation (Denzin & Lincoln, 2018). The interview guide consisted of open-ended questions designed to explore the emotional, financial, and social challenges that families face. The questions informed by the study's objectives and previous literature on family caregiving in pediatric cancer. The interviews were recorded with participants' consent, and detailed notes taken during the interview process. If a participant prefers not to be recorded, the researcher relied on comprehensive note-taking to capture their responses.

Data Collection Procedure

The data collection procedure began with obtaining ethical approvals. Once approved, participants will be recruited based on the study's inclusion criteria, with random selection ensuring fairness. Participants will be fully informed about the study and asked to provide consent. Interviews will

be conducted in a private setting within the hospital, ensuring confidentiality and comfort, with each session lasting approximately 45-60 minutes. The interviews will be recorded, with participant consent, and transcribed verbatim, while detailed notes will be taken if recording is not permitted. After each interview, participants will be debriefed, thanked, and reminded of their right to withdraw from the study at any time.

Data Analysis Method

The data was analyzed using thematic analysis, a widely recognized method for interpreting qualitative data (Braun & Clarke, 2006). This approach allows for the identification, analysis, and reporting of patterns or themes within the data. The first step in this process involves familiarization, where the researcher will read and re-read the interview transcripts to gain a deep understanding of the content. This will be followed by coding, where key features of the data will be systematically identified and labelled based on relevance to the study's objectives. After coding, related codes will be grouped into broader themes that capture significant aspects of the participants' experiences. These themes will then be reviewed and refined to ensure they accurately reflect the data and align with the research questions. Finally, the themes will be clearly defined and named, providing a structured narrative that captures the core findings of the study. This process will uncover important insights into the emotional, financial, and social impacts of pediatric cancer on families

RESULTS

The data analysis was conducted to explore the lived experiences, challenges, and coping mechanisms of caregivers in managing the healthcare needs of children diagnosed with cancer at the Cancer Diseases Hospital. The data for the study was collected through semi-structured interviews, allowing for an in-depth insight into the perspectives of the participants. The analysis was guided and bound by the study's objectives, focusing on the emotional, financial, social, and systematic factors that affect caregiving.

The thematic analysis approach employed in the study, organized and interpreted the qualitative data collected. The process involved coding the data, grouping related codes into subthemes, and consolidating subthemes into broader themes. The finalized themes capture the essence of the caregivers' challenges and provide a foundation for actionable public health recommendations. Frequency counts were used to quantify the prevalence of specific themes, ensuring a robust and structured presentation of findings.

The subsequent sections outline the thematic findings and their alignment with the study objectives, highlighting key insights that contribute to advancing health practices for caregivers and children with special needs.

Table 1 Subthemes Identified among the participants' comments

Subtheme	Comments	Percentage
Parental Stress and Anxiety	59	19%
Treatment and Transport costs	54	17%
Service gaps	47	15%
Loss of income	38	12%
Family relationship strain	36	12%
Access to Treatment	31	10%
Faith and Resilience	17	5%
Lack of family support	12	4%
Social networks	10	3%
Community disengagement	6	2%
Total	310	100%

Table 2 Main Themes from the Study

Main Theme	Comments	Percentage
Social Isolation	18	6%
Emotional Burden	95	31%
Financial Strain	92	30%
Coping Mechanisms	27	9%
Healthcare System Challenges	78	25%
Total	310	100%

Description of The Participants

The study included 51 participants who were primary carers for children admitted at the CDH. Participant selection was through purpose sampling methods, ensuring a diverse representation of the demographics and experiences of the caregivers.

Gender: the majority of the participants in the study were female (88%), a reflection of the traditional caregiving roles.

Age: The participants' ages ranged from 21 to 61 years, with the largest proportion (34%) falling in the 36-50 age group. Younger caregivers often reported higher levels of emotional distress due to a lack of prior caregiving experience, while older caregivers highlighted challenges related to physical exhaustion.

Educational level: Caregivers' educational backgrounds varied, ranging from no formal education to tertiary level (20%) and secondary level education being the largest proportion (48%). Those with higher education levels reported slightly better access to healthcare services and a stronger ability to navigate the medical system.

Employment Status: Many caregivers were engaged in self-employment or in informal jobs, such as small-scale trading and farming. A significant number indicated financial strain due to lost income or reduced work hours resulting from their responsibilities as a caregiver.

Married: Most caregivers were married (74%), with many describing support from their spouses. However, those who were single, separated, or widowed often reported greater challenges in managing the responsibilities of caregiving alone.

Socioeconomic Status: Most participants were from low-to-middle-income households, highlighting financial strain as a key factor in caregiving challenges.

Relationship to the Child: Predominantly mothers, followed by fathers and in some cases, extended family members (e.g., grandmothers, aunts). Mothers typically bore the primary caregiving with other household duties.

Core Themes and Subthemes

The analysis revealed five interconnected core themes that encapsulate the emotional, financial, social, and systemic challenges that caregivers of children admitted at the CDH face. Each theme is composed of several subthemes, highlighting the multifaceted challenges faced by caregivers. A total of 310 comments were recorded and aligned towards the themes that they were addressing. These findings provide a nuanced understanding of their struggles, coping mechanisms, and unmet needs.

1 Emotional and Psychological Impact

The emotional toll of caregiving was a dominant theme, with caregivers consistently reporting high levels of emotional distress. This theme captured the profound psychological toll of caregiving.

Parental Stress and Anxiety (19%)

Caregivers consistently reported heightened levels of stress and anxiety, describing persistent fear and worry about their child's health. These feelings were driven by the uncertainty of their child's prognosis, the complexity of the treatment regimens, and the fear of potential loss. One caregiver noted:

"The day I was told about the diagnosis, I felt very bad and I feel like my child will die any time since people say that cancer is not curable."

This shows that the caregivers go through a lot of stress as they provide care to the children. The emotional strain often manifested physically, with caregivers reporting sleeplessness, fatigue, and a loss of appetite. For many, the emotional burden worsened with time, leading to feelings of hopelessness and emotional depletion.

Family Relationship Strain (12%)

The caregiving role significantly disrupted family dynamics. Parents highlighted strained relationships with their spouses due to time and energy being disproportionately focused on the sick child. The siblings of the patient also felt neglected, leading to feelings of resentment within the family unit. A caregiver noted:

"It has brought a lot of challenges in the family. My other children have stopped school because we do not have enough money to send them to school. The cancer has also affected our business as a family because most of the time I am found in the hospital and our lifestyle has changed because they are unable to eat the way they used to."

Faith and Resilience (5%)

For many of the caregivers, faith was a source of reassurance and strength, a means of coping with the challenges of caregiving. Religious and spiritual beliefs helped them find meaning and hope during difficult times. One participant shared:

"It was heartbreaking... I had to undergo a lot of counselling and prayer for me to accept the situation, and now we look forward to recovery as a family... Men of God should be available whenever one is down to strengthen us from this situation."

However, some caregivers acknowledged that while faith provided temporary comfort, the overwhelming demands of caregiving often required additional emotional and psychological support.

4.5.2 Financial and Logistical Burdens

Financial strain emerged as one of the most pressing challenges for caregivers, significantly affecting their ability to provide care and sustain their households. Most of them indicated a challenge to feed themselves or provide alternative meals for their children on the ward.

Treatment and Transport Costs (17%)

The high cost of transportation to and from the hospital, coupled with the out-of-pocket expenses for treatment, placed an extra burden on caregivers. Many families depleted their savings or relied on handouts from well-wishers to cover these expenses. One caregiver explained:

“It has brought about financial setbacks in which all our investments have been depleted, due to travel, medication, and food.”

Loss of Income (12%)

Caregiving responsibilities often require parents, particularly mothers, to reduce working hours or to leave their jobs. This loss of income added to the financial strain, making it difficult for them to afford basic needs. A participant noted:

“Since my child’s diagnosis, I have incurred a loss in the sense that my business is down...money is not flowing as it used to since I lost the business due to my being in the hospital for some time.”

4.5.3 Healthcare System Challenges

Caregivers frequently encountered systemic barriers within the healthcare system, which worsened their struggles.

Service Gaps (15%)

Delays in diagnosis, insufficient hospital resources, and long waiting times were common frustrations. Many caregivers expressed disappointment with the healthcare infrastructure, citing the lack of specialized care, broken-down equipment, and stock outs of medications. One caregiver shared:

“I would love the hospital to speed up investigations because it 3 months since the time my child was diagnosed with cancer but no treatment has been commenced.”

Access to Treatment (10%)

Geographic and financial barriers made it difficult for caregivers to access consistent care for their children. Caregivers from rural areas faced particularly steep challenges, as they often had to travel long distances to reach the Cancer Diseases Hospital.

“The hospital should be speeding up the process of treatment because the condition does not wait for any delay. the hospital does not always have drugs readily available and other hospital things like colostomy bags because it is very expensive for us who are not doing anything.”

4.5.4 Coping Mechanisms

Despite the challenges, caregivers employed various coping mechanisms to navigate their caregiving responsibilities.

Faith and Resilience

As previously mentioned, faith played a pivotal role in helping caregivers maintain hope. Some also relied on personal resilience and inner strength to manage the day-to-day demands of caregiving.

Social Networks (3%)

Support from friends, extended family, and community groups provided much-needed relief for some caregivers. These networks often helped with practical needs such as food, and occasional donations of daily needs such as toiletries to the wards. One caregiver explained:

“Life was already hard for me as a new divorcee and things just became worse financially when my son was diagnosed with cancer. I depend on handouts from well-wishers as I have no other means.”

However, not all caregivers had access to such support, highlighting disparities in community engagement.

4.5.5 Social and Community Factors

Social isolation and a lack of support were recurring themes, further compounding the challenges that the caregivers faced.

Lack of Family Support (4%)

Many caregivers expressed disappointment at the lack of involvement from the extended family members. Cultural and Financial reasons often prevented relatives from stepping in to help, leaving the primary caregivers to manage alone.

“...due to my child being in the hospital, my family stopped being supportive after the child was diagnosed with cancer”

Community Disengagement (2%)

Stigma and a lack of understanding about childhood cancer led to social withdrawal for some families. Caregivers described feeling alienated or judged by their communities. One caregiver remarked:

“It is very disturbing since he was diagnosed with this condition, their life has not been the way it used to be. My son is unable to socialize with others the way he used to. Stigma in the community is also a challenge as people are always afraid of my child and us as a family.”

These themes paint a comprehensive picture of the lived experiences of caregivers at the CDH, highlighting the emotional, financial, and systemic challenges they face while admitted at the hospital. The findings underscore the urgent need for holistic intervention, including enhanced healthcare services, financial support mechanisms, and community-based caregiver programs.

Comparative Analysis

The caregiving experiences varied significantly across demographic and socioeconomic groups, highlighting differences in challenges caregivers face at the CDH and their adopted coping mechanisms.

1. Gender Differences

Female caregivers (88%) were overwhelmingly responsible for caregiving roles. Many reported emotional distresses, with a focus on meeting their child's daily needs at the hospital.

"Since the time my child was diagnosed with cancer, our life has not been the same. I spend most of my time in the hospital, as I must stay with my child. I am unable to socialize with others since I spend most of my time in the hospital."

Male caregivers expressed challenges that mainly related to financial pressures and provision for the family while supporting their child's treatment.

"It has been especially hard for me as a father and when I think about it a lot, I feel like having a mental breakdown."

2. Age-Related Challenges

Younger caregivers (21-35 years) reported higher emotional distress due to them having limited caregiving experience, coupled with financial instability.

"Since my child was diagnosed with cancer, it has been painful to both the child and us her parents, since my child was born, I have never seen someone in so much pain, and it is new in the family."

Older caregivers frequently mentioned physical exhaustion as a challenge, coupled with the emotional strain of long-term hospital stay and caregiving.

"Life has been so overwhelming and I cannot understand why all this happened to me. I usually feel like giving up but I know that my grandchildren will suffer without me."

3. Educational and Socioeconomic Differences

Education level

Caregivers with higher levels of education such as those with tertiary training (20%) demonstrated a better understanding of treatment protocols and healthcare navigation. They understood the diagnoses and were more willing to take up the treatments prescribed for their child.

"It is very important for other mothers to adhere to the doctor's orders to prevent relapse and observe review dates."

Those with primary or secondary education struggled more with medical communication and advocacy. Some struggled with the child's diagnosis and some still attribute it to other issues outside of it just being a medical condition.

“I feel like someone has bewitched my child and it does not matter what anyone says because I even know the person behind it. I am very angry and it has brought tension in our family”

“It was hard for us as a family to accept that my son had cancer. I requested for the hospital to discharge us so that we could take the child to a witch doctor as we believed that the child was bewitched.”

4. Economic Status

Low-income caregivers frequently reported financial strain, with many wiping out their savings on relying on handouts from family and well-wishers to sustain themselves and meet their treatment and transportation needs.

“Since my child was been diagnosed with cancer, life has not been easy, feeding has been a challenge. We are not able to do some piece works; this is challenging as the piece works could help in our financial situation.”

The comparative analysis highlights how age, gender, education, and economic status shaped caregivers’ experiences. These findings provide a foundational understanding of the diverse challenges that caregivers at the CDH face, offering context for the core themes presented.

DISCUSSION

The findings of this study provide an in-depth understanding of the lived experiences of caregivers for children with cancer at the Cancer Diseases Hospital. Through the examination of the emotional, financial, social, and systemic challenges faced by caregivers, this research highlights critical gaps in support systems and healthcare services. Caregivers constantly reported overwhelming stress, compounded by financial strain and logistical barriers to their access to care. The study also illuminated the role of faith and social networks in providing emotional resilience, albeit insufficient in addressing the broader challenges. Additionally, systemic issues in the provision of healthcare, including delayed diagnoses and resource limitations, further exacerbated the caregivers’ struggles at the CDH. The chapter contextualized these findings, situating them within the existing literature and exploring their implications for public health policy and practice.

The study revealed that caregivers experienced significant emotional distress, with stress and anxiety emerging as dominant themes, with many caregivers describing the relentless fear of losing their child and the strain of navigating uncertainty. These findings are not unique to Zambia; similar challenges have been reported across sub-Saharan Africa, where caregivers often face compounded psychological burdens due to limited support systems (Mweemba et al., 2021). Globally research has shown that prolonged caregiving increases the risk of anxiety and depression among parents of children with chronic illness (Singh et al., 2022).

Feelings of isolation were also prevalent, particularly in the absence of formal mental health support. The findings mirror those from a study that revealed disrupted family dynamics, including strained marital relationships and neglected siblings (Day et al., 2015). As one caregiver in our study put it:

“Sometimes I feel like giving up because this situation is so unbearable for me and I feel alone.”

Interestingly, faith and resilience came up repeatedly as coping strategies. Many caregivers leaned on their spiritual beliefs to find hope in the face of adversity. This finding was not surprising as studies from sub-Saharan Africa and beyond highlight the vital role faith plays in helping families cope with serious illnesses. Still, while faith provides emotional relief, it fails to address the more practical or systematic challenges that caregivers face (Walubita et al., 2018; Dreer et al., 2019).

Money or the lack of it was a recurring challenge for caregivers in the study. Treatment and transportation costs often left families scrambling to make ends meet, forcing most to either sell assets or deplete their business capital. This finding was mirrored by studies in other countries in the region, where out-of-pocket healthcare expenses was noted to have the potential to push families into poverty, Nortey et al., (2017), in their study reported that family caregiving in Ghana imposes a significant economic burden, with high direct costs and productivity losses. A caregiver in our study shared this heartbreaking account:

“We come to the hospital monthly and I am forced to spend most of the money I make from selling animals and farm produce on transport and food.”

To add to that, many caregivers had to quit their jobs or cut back on work hours to take care of their children. Similar patterns have been observed in regional studies from Kenya and Nigeria, where caregiving disproportionately affects women’s ability to earn an income (Asuquo et al., 2017; Oloo et al., 2021). Globally, research underscores how this financial toll can have lasting consequences, not just for caregivers but for entire households, Reinhard et al., (2020), reported that caregiving has significant financial and health impacts, with 38% reporting financial strain attributed to the role.

Healthcare system challenges were another major theme. Delays in diagnosis, lack of resources, and overcrowded facilities were common complaints among caregivers. These issues are not unique to Zambia; they are common across the region, where limited healthcare infrastructure makes it difficult to provide timely and adequate care (Walubita et al., 2018). One caregiver summed it up as:

“Delays in starting patients on treatment is making patients die even before commencing treatment, the doctors should speed up the investigation process.”

For caregivers in rural areas, the situation was even worse. Long travel distances and high transportation costs created additional barriers to accessing care, as seen in similar studies from Uganda and Ethiopia (Kipp et al., 2007; Bachani et al., 2017).

Social isolation and stigma were brought up repeatedly in the interviews. Many caregivers described feeling alienated, not just by their communities but sometimes by their own extended families. This is consistent with other local studies documenting how misconceptions about childhood cancer can lead to discrimination and withdrawal of support (Sibulwa et al., 2019). A caregiver in the study shared this painful experience:

“Cancer has brought a lot of challenges...It has brought a lot of division in the family (stigma) and no more unity is being seen.”

On the flip side, caregivers with strong social networks, like church groups or community organizations, spoke about how much they relied on that support. This aligns with findings from Walubita et al., (2018), who showed that the community groups play a vital role in reducing caregiver burden.

The findings of this study resonate with both regional and global research on caregiving. Emotional distress, financial strain, healthcare system challenges, and social isolation are recurring themes in studies from Zambia (Chiluba et al., 2017) and across sub-Saharan Africa (Kipp et al., 2007; Bachani et al., 2017). Overall, the findings of research work into caregiving, highlight the need for holistic interventions, combining public health policy with community-based initiatives.

Implications for Public Health Practice

The findings of this study have several significant implications for public health practice, particularly in the support systems and healthcare experiences for caregivers of children with cancer. These insights underscore the important need for a multi-faceted approach addressing the emotional, financial, systemic, and social challenges.

1. Addressing Emotional and Psychological Needs

Caregivers in the study consistently reported emotional distress, highlighting the urgent need for mental health intervention for carers at the CDH. Integrating psychological support services into cancer care could include:

- **Counselling Services:** Establishing on-site counselling at healthcare facilities (the children’s ward at the CDH) to support caregivers during treatment visits and during hospital stays.
- **Peer support groups:** There need to be efforts to facilitate caregiver support networks where participants can share experiences and coping strategies.
- **Psychoeducational programs:** Offering education on stress management and resilience building tailored to caregiving contexts.

These interventions align with global recommendations or holistic care and could significantly alleviate the mental health burden faced by caregivers.

2. Financial and Economic Interventions

The study identified financial strain as a major challenge for caregivers. To address this:

- **Subsidies for Transport and Treatment:** Public health policies should prioritize financial aid programs for families travelling long distances or incurring high out-of-pocket expenses.
- **Inclusion in Health Insurance:** There is a need to expand insurance coverage to include caregiver-related expenses as this could reduce economic hardships.

- **Income Replacement Programs:** Developing community-based income support programs, such as caregiver stipends or the use of Community Development Funds (CDF), could mitigate the loss of earnings associated with caregiving responsibilities.

Such interventions would help reduce inequalities in access to care, particularly for low-income families.

3. Healthcare System Improvements

Caregivers highlighted systemic challenges, such as delays in diagnosis and limited resources. Addressing these requires:

- **Decentralization of Cancer Care Services:** the establishment of satellite centers closer to rural communities to improve access and reduce travel-related burdens.
- **Resource Allocation:** ensuring adequate staffing, diagnostic equipment, and essential medicines at healthcare facilities.
- **Streamlined Care Pathways:** the implementation of policies aimed at the reduction of delays in diagnosis and treatment initiation, particularly for pediatric cancer patients.

These improvements could have a strengthening impact on the healthcare system and healthcare delivery and enhance patient outcomes.

4. Community and Social Support

Social isolation and stigma were significant barriers for caregivers in this study. To address these:

- There is a need to drive Community Awareness Campaigns, and public health initiatives to increase awareness about childhood cancer, reducing stigma, and promoting inclusivity.
- **Strengthening Faith-based and Community Network:** Partnerships with religious and community organizations should be encouraged, as they provide emotional and practical support to caregivers.
- **Volunteer programs:** the mobilization of community volunteers to assist caregivers with the day-to-day tasks, such as transportation or child supervision.

These strategies could foster a more supportive environment for caregivers, reducing their sense of isolation.

The study's findings have relevance beyond Zambia, offering key insights for similar contexts in low- and middle-income countries. By addressing caregiver challenges, this work contributes to achieving:

- **Sustainable Development Goal 3 (Good Health and Well-Being):** by improving cancer care delivery and caregiver support
- **Sustainable Development Goal 10 (reduced Inequalities):** ensuring equitable access to healthcare and financial support for vulnerable populations.

Strengths of the study

The study has several strengths that enhance its credibility and contribution to public health knowledge:

- **Rich Qualitative Data:** the use of semi-structured interviews provided in-depth insights into the lived experiences of caregivers, allowing for a nuanced understanding of their challenges and coping mechanisms.
- **Diverse Participant Demographics:** The inclusion of caregivers from various age-groups, educational backgrounds, and geographic locations ensured a broader perspective on caregiving experiences.
- **Context Specific Insights:** through the focus on caregivers at the Cancer Diseases Hospital in Zambia, the findings offer valuable, localized insights that can inform policy and intervention design in similar resource-limited settings.
- **Alignment with Regional and Global Contexts:** The findings align with and expand upon existing regional and global research, contributing to a more comprehensive understanding of caregiver challenges in low- and middle-income countries.

Study Limitations

While the study provides valuable insights, certain limitations should be acknowledged:

- **Single Study Site:** The research was conducted at a single institution, which may limit the generalizability of the findings to caregivers in other healthcare settings or regions within Zambia.
- **Potential Selection Bias:** The participants for the study were recruited from a hospital setting, which may have excluded caregivers who could not afford hospital visits or chose alternative care pathways.
- **Cross-Sectional Design:** The study captures experiences at a single point in time, limiting the ability to explore how caregiving challenges and coping mechanisms evolve.
- **Self-Reported Data:** The reliance on self-reported information may introduce recall bias, as participants might unintentionally underreport or overemphasize certain aspects of their experiences.

While the limitations exist, the study's strengths ensure its findings remain a valuable contribution to understanding the challenges faced by caregivers of children with cancer. Future research can build on these insights by exploring longitudinal trends and including multiple healthcare settings.

Conclusion

The study sheds lights on the multifaceted challenges faced by caregivers of children with cancer at the Cancer Diseases Hospital in Zambia. The findings highlight the profound emotional, financial, social, and systemic burdens experienced by caregivers, as well as their reliance in navigating these difficulties.

Key themes included high levels of emotional distress, significant financial strain, systemic barriers within the healthcare system, and social isolation exacerbated by stigma. Despite the challenges, caregivers demonstrated remarkable adaptability, often relying on faith, resilience, and limited social networks for support.

These findings underscore the urgent need for comprehensive, caregiver-centric interventions that addressing both immediate caregiving needs and a broader systemic gap in healthcare and community support. By taking actionable steps, policymakers and public health practitioners can significantly improve the well-being of caregivers and the outcomes for the children they care for.

Recommendations

- Establish Caregiver Counselling Services, providing on-site counselling at hospitals to help caregivers cope with emotional stress and anxiety.
- Create Peer Support Groups, there needs to be facilitation of support networks where caregivers can share experiences and strategies.
- Introduction of Subsidies on transport and treatment costs, introducing targeted financial assistance programs for caregivers travelling long distances
- Expansion of health insurance coverage, ensuring that caregiver-related expenses, such as travel and accommodation included in health insurance policies
- Provision of small allowances as caregiver stipends, compensating for lost income due to caregiving responsibilities.
- Decentralization of cancer care through the establishment of satellite clinics in rural areas to reduce travel burdens and improve access to timely care.
- Strengthening resources at existing facilities: allocation of resources to address diagnostic and treatment delays, including hiring more healthcare personnel and improving infrastructure.
- Development of policies that allow for streamlining of care pathways, minimizing delays in diagnosis and treatment initiation.
- Launch public health campaigns aiming to raise awareness about childhood cancer, reducing stigma and increase community support for affected families.
- Strengthen faith-based and community networks to provide emotional and practical support for caregivers.
- Encourage community members to volunteer, assisting caregivers with daily tasks, such as transportation or child supervision.
- Integrate caregiver support into national health policies, ensuring caregivers needs are explicitly addressed in Zambia's healthcare strategies.

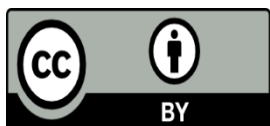
- Encourage longitudinal research to explore how caregiving challenges and coping mechanisms evolve over time to inform future interventions
- Regional collaborations to share insights with neighboring countries to develop a cohesive strategy for supporting caregivers in sub-Saharan Africa.

By addressing the challenges identified in this study, stake holders can improve the quality of life for caregivers and enhance the overall effectiveness of pediatric cancer care. This work serves as a foundation for future research and policy development aimed at creating a more supportive and equitable healthcare environment.

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