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Challenges and coping strategies among caregivers of children with cancer receiving care at a national referral hospital in Kenya

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Abstract

Background The number of children diagnosed with cancer is expected to increase by 2050. The caring aspect of these children is usually left to members of the family, more so the mothers. Caregivers are usually faced with various challenges, such as financial issues, social stigma, and emotional and psychological issues. Caregivers use various coping strategies to manage the challenges they experience in the caring process, which can be positive or negative coping strategies.

Objective To explore the challenges and coping strategies of caregivers of children with cancer receiving care at a national referral hospital in Kenya.

Methods This study employed a descriptive phenomenological approach to explore the challenges and coping strategies of caregivers of children with cancer receiving treatment at a national referral hospital in Kenya. Purposive and snowball sampling techniques were used to select 44 participants for five focus group discussions (FGDs) conducted between October and December 2023. The data were analysed via inductive thematic analysis.

Results Four themes arose from the challenges experienced, which included psychological, financial, treatment-related, and social/family-related issues. These eleven subthemes included stress, depression, lack of transport, lack of food, loss of employment, treatment delays, and marital issues, among others. Two themes related to coping strategies were positive adaptation and denial, which were highlighted as negative coping strategies. Positive coping included praying, crying, talking to people, and seeking help.

Conclusion Caregivers of children with cancer undergo various challenges and apply various coping strategies to try and adapt to their new normal. Reinforcing positive coping strategies and helping caregivers utilize other coping strategies, such as the use of support groups, could help them better care for their children.

Keywords Caregivers, Children, Cancer, Challenges, Coping strategies

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Introduction

Globally, the number of cancer diagnoses among children is expected to increase to 13.7 million between 2020 and 2050, with 3.3 million in low-resource settings, including sub-Saharan Africa [1]. By 2050, Africa is projected to harbour approximately half of the world's paediatric cancer cases [2]. In Kenya, childhood cancer affects approximately 3,000 children, and its incidence is expected to increase by 2050, with the incidence of leukaemia, Wilms tumour, and lymphoma remaining predominantly high [3–5].

The increasing number of cases of childhood cancer increases the need for care. At present, in most societies, family members are the primary caregivers of children with cancer [6]. In particular, mothers often step into the caring role, which can be overwhelming as they try to juggle motherhood and other responsibilities at home [7–9]. Consequently, parents have lost their source of livelihood and income due to resigning from work, being laid off owing to absenteeism and the excess amount of time taken off work, and closing businesses because of frequent hospitalisation [10]. In addition, the burden of care is exacerbated by the high cost of treatment, improved cancer management and increased recovery period.

Evidence shows that caregivers of children with cancer experience psychological and emotional distress, including stress, anxiety, worrying, emotional strain, and depression [11]. This is in addition to the documented negative association of caregiving with quality of life among caregivers of children with chronic illnesses, especially cancer [12]. In addition, cancer diagnoses have been shown to affect family dynamics, with the mother spending most of her time in the hospital with the sick child while the father or other family members taking care of the siblings [13–15]. Sometimes, prolonged periods of the mother's absence lead to siblings feeling neglected [15]. Additionally, increased dependence or reliance on relatives or friends for support has caused strain, with some parents experiencing social stigma, alienation, and loneliness [16].

With the increased burden of care, caregivers of children with cancer use various coping strategies to adapt to their new roles at diagnosis and throughout the treatment trajectory. Several studies highlight the key role of social support from family, friends, and the community [17–19], while others note the role of spirituality through prayers with the belief that God would heal their children [18]. In addition, healthcare providers remain key players in helping caregivers cope with their children's cancer by providing adequate information about the diagnosis and support during treatment [19].

In particular, Kenya is experiencing an increased incidence of childhood cancers, resulting in an increased burden of care, which is borne mostly by caregivers, who are usually family members. The effective treatment and care of children with cancer are dependent mostly on these caregivers, who provide real-time support to sick children, including feeding, adherence to medicines, personal hygiene, and liaison with health providers. With caregivers experiencing a myriad of challenges, there is a need to better understand these challenges and their coping strategies to devise effective interventions to support the caregivers of children with cancer to offer appropriate support to their children, family and community during the disease trajectory. Hence, this study aimed to explore the challenges and coping strategies of caregivers of children with cancer receiving care at a national referral hospital in Kenya.

Method

Study design and setting

This study employed a descriptive phenomenological approach to understand the challenges and coping strategies among caregivers of children with cancer receiving treatment at a national referral hospital in Kenya. This design was chosen because it allowed researchers to use a Lazarus and Folkman transactional model to explore the experiences of individuals within their experiential world and how individuals make sense of the world to provide insightful accounts of their subjective experiences [20]. The referral hospital is one of two public facilities that manage children with cancer and receives most of the referrals across the country, allowing recruitment of participants from various sociodemographic backgrounds.

Sampling and participant selection

Purposive and snowball sampling techniques were used to recruit forty-four (44) caregivers of children with cancer from the paediatric oncology department of the referral hospital. We included only caregivers who were the primary caregivers of children with cancer and who were 18 years and older at the time of the study. Information about the study was disseminated through the nursing department and by word of mouth through the caregivers. The principal investigator explained the purpose and protocol of the study to those interested, and the study participants provided written informed consent. This was done face-to-face in the paediatric oncology units, and out of 72 participants who were engaged, 44 (66.1%) consented and 28 (38.9%) declined, citing time constraints.

Data collection

Five focus group discussions (FGDs), each comprising 7–15 caregivers, were conducted between October and December 2023. The first author (DVWM), a female experienced qualitative researcher and an oncology lecturer, conducted the FGDs, supported by a research assistant trained in qualitative research who took field notes during the focus group. The FGDs were guided by a semi-structured interview guide with follow-up questions and probes used to discern the caregivers' lived experiences of caring for children with cancer (Supplementary Material S1). The relevance of the content of the interview guide was assessed by two qualitative and subject matter experts. The interviews were conducted in both English and Swahili in the paediatric oncology unit and lasted approximately 75 min. At the start of each interview, consent was obtained from each participant to audiotape the interviews, and the participants were reminded of their rights to participate in the discussions. Data saturation was attained with the fourth FGD which revealed no additional information from the participants. To ensure the completeness of the data, the researcher conducted one more FGD, bringing the total number of participants to 44.

Data analysis

Audiotaped data were transcribed verbatim and imported to NVivo qualitative analysis software version 22 (QSR International, Victoria, Australia) for the inductive thematic analysis [21]. First, the researchers read and reread the transcripts and listened to the audio. Second, the data were coded separately by the principal investigator and a research assistant. The initial codes generated were discussed between the two coders and with the research team for comparison and concurrence and to identify any initial themes. At this stage, some codes were dropped, while some were modified. Third, further coding was performed, and similar codes were grouped to form themes and subthemes. Next, the data were reviewed again to identify the data that supported the identified themes to ensure that the identified themes were grounded in the data.

Rigour

To ensure trustworthiness, we used various strategies to ensure credibility, dependability, confirmability and transferability, as proposed by Lincoln and Guba [22]. First, purposive sampling was used to identify the study participants—caregivers of children with cancer receiving treatment at a national referral hospital in Kenya—who were involved in the daily care of the children, hence providing a more accurate account of their lived experiences. In addition, all the FGDs were audio-recorded for verification, and two investigators coded the data to allow investigator triangulation.

Second, the study was conducted with caregivers of children receiving care at a referral hospital, which allowed the inclusion of caregivers from different parts of the country, increasing the credibility of our study. Additionally, to further ensure credibility, a semi-structured discussion guide was used, a diverse group of researchers collected and analysed the data and analyses were discussed at different points to reduce potential researchers' biases. Third, thick descriptions of caregivers' challenges and coping strategies when caring for children with cancer are provided to illustrate the identified themes, and a detailed description of the context is provided to allow for the potential transferability of the findings. Finally, negative cases—unhealthy coping strategies that may be detrimental to the patients or caregivers—were analysed and reported. In addition, the study reporting adheres to the 32-item checklist of consolidated reporting guidelines for qualitative research [23].

Results

Participants' demographics and characteristics

Five focus groups involving 44 caregivers of children with cancer were conducted. Most of the caregivers were women (n=38, 86.4%), mothers (n=36, 81.8%), married (n=29, 65.9%), and unemployed (n=29, 65.9%). Of the 44 children being cared for, 28 (63.6%) were male, 14 (31.8%) were firstborn, and 22 (50%) were not attending school. Nineteen (43.2%) children had leukaemia, eight (18.2%) had lymphoma and six (13.6%) had nephroblastoma. The mode of therapy was mostly chemotherapy (n=36, 81%), with 20 (45%) patients having been diagnosed within the last six months.

Six main themes—four on caregiving challenges/stressors and two on coping strategies—were identified, each further classified based on subthemes (Fig. 1). Each of the themes is discussed in detail, including illustrative quotations from participants identified by the focus group and participant's number, sex (male, M or female, F) and age.

Themes and subthemes

Challenges experienced when caring for children with cancer

Theme 1: psychological issues

Caring for a child with cancer is a profound journey that often brings to light the issues affecting mood, thinking, and behaviour, such as depression and stress. Caregivers reported experiencing stress related to the diagnosis and treatment. Others expressed being depressed as they tried to come to terms with the diagnosis.

> *"I didn't know how to deal with the.... (silence) with the diagnosis. I was stressing about the treatment and its effects, he was vomiting, wasn't eating...and I didn't know what to do. It stressed me." FGD1 Participant (P)3, Female (F), 23 years.*
>
> *"I am asking myself if my life will be this way until when. I am asking if this cancer will end; I am eager for it to end even today, so I continue with my life. It*

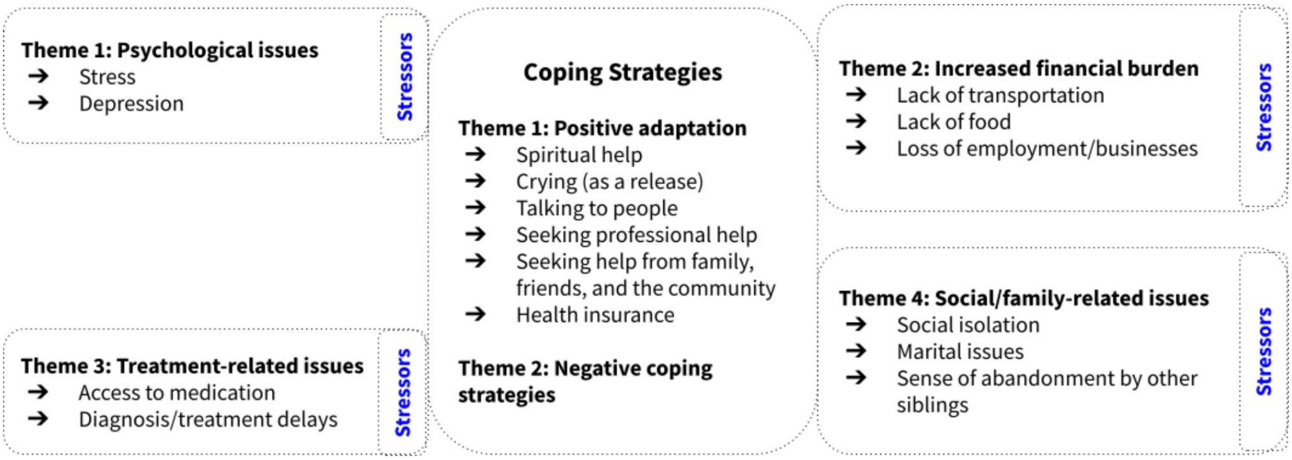

Fig. 1 Themes and subthemes

> *is very hard what I am going through (wipe tears)." FGD4 P4 F,31 years.*
>
> *"I was depressed, I still have pains. It is still hard for me to believe my child has cancer." FGD2 P4, F, 30 years.*

Theme 2: increased financial burden

The high cost of cancer diagnosis, treatment, transport, and follow-up, especially due to the inaccessibility of services in the nearest health facilities, poses financial challenges for caregivers. Some caregivers found it challenging to meet their transport cost to the hospital for treatment, which made the children miss appointments and delay treatment.

> *"You are supposed to return the child to the hospital, and you do not have money. You will be forced if it is a goat you sell… When you know you are going somewhere, clinic Monday you will have to sell that goat; you go sell you get fare from Ukambani, our home is Makueni…before we used to pay for Kenyan Shillings 500 (US$ 3.9) in 2016; now, it has gone up and reached Kenyan Shillings 650 (US$ 5)." FGD5 P11, F, 35 years.*

Even with the available funds channelled toward cancer treatment, caregivers found it an uphill task to provide nutritious food for their children during hospitalisation and for those at home.

> *"You get, at times, the child asking you questions until you can't answer. 'Mum, will I eat this today?' you wonder what you will do to the child. When you look at your phone [mobile banking], you even don't have a shilling [money] to buy something else…." FGD4 P7 F, 28 years.*

With the loss of sources of income due to long hospital stays, some of the caregivers lost their jobs, and others closed their businesses, making their financial woes worse.

> *"I was at work when this sickness started, I was using a card [National Health Insurance Fund (NHIF) card], right now you know work ended, right now I am not going to work, I do not have a job… paying for treatment and caring for the other expenses has been tough (sigh)." FGD2 P7 M, 40 years.*

Theme 3: treatment-related issues

A timely and correct cancer diagnosis is critical to a successful treatment outcome. For some caregivers, it took months before the child's diagnosis was established due to an inadequate level of knowledge on cancer diagnosis among healthcare workers, which led to a delay in the initiation of treatment.

> *"The doctor who did the MRI [magnetic resonance imaging] told us there is a small growth that will disappear. We did not know it would come to be a cancer and we went home, that is in May this year until now in October, when it came to be known that he had a brain tumour, something we did not expect." FGD2 P7 M, 40 years.*

Cytotoxic drugs are usually expensive and are only dispensed by chemotherapy administration centres or specific pharmacies due to their toxic nature. Participants noted that most of the time, the hospital did not have the prescribed medicines. They said that they were thus forced to source these medicines from private pharmacies outside the hospital, most of which do not stock chemotherapy drugs, making it difficult to access the required medications at affordable cost and within reach.

> *"The doctor says, 'Your medicine is not there.' That doctor writes a prescription, and he does not know if you do not have that money, and he doesn't tell you how much those medications cost and where to get them. I do not know Nairobi [where the hospital is located], so I looked for a doctor who knows where I can get the medicine… (wipe tears)." FGD3 P2 F, 24 years.*

Theme 4: social/family-related issues

Cancer treatment is typically lengthy, and caregivers require all available social, emotional, and financial support. The nuclear family is the first source of support for caregivers, but if the bond is not strong, conflict is likely to occur. Most participants noted experiencing difficulties in their marriages after the diagnosis and because of prolonged episodes of hospitalisation since the mothers (caregivers) stayed with the sick child. Some reported undergoing periods of separation.

> *"I called the child's father and told him the diagnosis. He stayed for two days, and on the third day, he told me, 'I sat with my family, we discussed, and we saw our family has never had a sickness like this. Therefore, we agreed when you leave the hospital, you will return to where you were born.'" FGD1 P5 F, 30 years.*

As the treatment journey continues, family dynamics change, and as more attention is given to the sick child, the sibling starts to feel the void. Caregivers reported that the siblings felt neglected, with their sick siblings being favoured or loved more.

> *"…. It's easy to make your small kids hate you out of nothing because they always ask me 'Mum, why don't you always take me to the hospital….It's as if mum you like [name of the child] much.' not that I love her, it's her problems that make me draw near her, they see as if I am not taking care of them…" FGD5 P10 F, 42 years.*

Extended family, friends and the community offered support during the initial phase of diagnosis and treatment, but this gradually changed over time. The participants expressed being isolated by some family members and friends, with some refusing to answer their calls, while others even blocked their calls.

> *"Some family members such as my sisters and even brothers are staying away from us. They do not even call or even help me out with the other children at home." FGD5 P1 F, 29 years.*

Coping strategies

Theme 1: positive adaptation

When presented with a challenge, it is human nature to look for solutions and adjust to the new situation. People use a variety of good coping tactics that appear appropriate for the scenario. Crying, an emotional response, is used on various occasions, for example, after receiving good news, when one is happy when one has experienced a loss, and after receiving life-altering news. Caregivers reported crying after their child was with cancer, which they perceived to be tantamount to a death sentence; therefore, they cried as a way of coping with the emotional response to the diagnosis.

> *"When I heard, me I cried, I was shocked and said nothing 'wooi,' it is the end. I just heard about cancer, I said… I cried; I saw as if it was the end." FGD5 P6 F, 27 years.*

People believe in more spiritual beings for comfort and as a source of strength. This is usually expressed by holding prayer sessions in the church, at home, and in the hospital, individually or as a group. Some caretakers prayed to God for strength, believing he would heal their children. Praying comforted the caregivers and provided the strength needed to care for their children.

> *"…I felt like I didn't know if I would manage, so it's just God to help me. I left it there for God to help me…. the only thing that gives me hope is God." FGD1 P2 M, 52 years.*

Most caregivers sought help from professional counsellors and social workers to cope with the emotional burden of caring for their children after the cancer diagnosis. In addition to emotional support, social workers also advocate for caregivers, for example, to ensure that they have health insurance.

> *"Counselling helped me. The counsellor also came to the ward, and we talked, that's how I was able to take the news of the diagnosis (sigh). I can focus better on caring for my child." FGD4 P4 F, 31 years.*
> *"Mostly social workers, because they helped us, we stayed here…for like nine months and the bill was enormous, so he helped us get the card [NHIF card] it matured, and it paid our bills." FGD4 P6 F, 26 years.*

Social support was multidimensional, as it came from several sources and in several forms. Some caregivers felt that their weight increased after talking with friends, family members, and the community. Talking to other people who helped the caregivers cope with their child's diagnosis provided them with a sounding board.

> *"I am very talkative. Therefore, I will go to my bed-mate, then I go to another one, and I talk, and she talks. This has helped." FGD2 P4 F, 30 years.*

As much as cancer diagnosis puts a strain on the relationship between the caregivers and family members, for some, the relationship was strengthened. The family rallied behind the caregivers and offered support in the form of financial help and care for the other children.

> *"When I get stuck somewhere, my sister and my in-law are the ones who try and stand with me…they send me money to buy some necessities for my child." FGD5 P1 F, 29 years.*

For some of the caregivers, the adage "it takes a community to raise children" became true, and they turned to prayer and fundraising to lessen their financial burden. During times of hospitalisation, friends also paid visits.

> *"The community has been supportive, and when you see people coming to help you even without you informing them, it is something I appreciate. Like my church held a fundraising for me, I (sigh) thank God for them." FGD5 P3 M, 47 years.*

With insufficient income and rising medical bills, the health insurance fund relieves the caregiver's burden by paying medical bills and purchasing medication for their children.

> *"If I didn't have NHIF, I don't know what I would have done, it has helped a lot." FGD4 P11 F, 29 years.*

However, despite paying premiums for the NHIF, this was not enough to cover all the costs. Some caregivers reported incurring additional out-of-pocket expenditures for costs not covered by health insurance.

> *"The NHIF only pays for six chemotherapy sessions, the doctor has written seven chemos [chemotherapy], and I am the only one to look for the money, and the drugs are expensive." FGD2 P4 F, 30 years.*

Theme 2: negative coping strategies

When faced with difficult situations or emotions, some people use denial to avoid situations. When parents were first given the initial diagnosis of cancer, some went into denial, and others have yet to come to terms with the diagnosis despite instituting treatment. Caregivers were wondering where the child could have gotten the cancer from.

> *"I never accepted the child has cancer because I wondered if a small child will get cancer from where, and it's something I have never heard of at home. Where did he get it from?" FGD4 P9 F, 39 years.*

Discussion

Cancer diagnosis can be traumatic for any patient and the family at large. Most of the caregivers of children with cancer question the origin of the cancer. This study explored the challenges and coping strategies of caregivers caring for children with cancer in Kenya.

Our study highlights that caring for children with cancer is an exhausting but fulfilling full-time job for most caregivers. Caregivers must overcome several challenges, such as psychological, financial, diagnostic and treatment, and social issues. In addressing these issues, caregivers are supported by strategies such as seeking and receiving help from counsellors, medical social workers, and social circles (family, friends, and community), subscribing to health insurance, and seeking spiritual interventions.

The challenges the caregivers in our setting experienced were similar to the challenges experienced by most caregivers in other low-resource settings in providing care for children with chronic illnesses, especially cancer [24]. In our study, caregivers reported experiencing stress and sometimes feelings of depression, especially at the time of diagnosis and during the prolonged, challenging treatment period. Similarly, previous studies have shown that caregivers experience sadness, fear, anxiety, and stress for multiple reasons, such as worrying about their child's response to the treatment, about other children being left behind at home, and being financially friendly [11]. The experience of psychological and emotional distress is negatively associated with caregivers' quality of life [12]. This highlights the need for continued support to caregivers throughout disease progression. In this study, caregivers noted that receiving support from professional counsellors and medical social workers and talking to friends, family, and their social circle is important in coping with the psychological and emotional issues of caregiving for children with cancer [17–19]. Professional help and social capital are effective ways of addressing emotional and psychological problems in different settings [19, 25, 26]. In addition, healthcare providers remain key players in helping caregivers cope with their children's cancer by providing adequate information about the diagnosis and providing support during treatment [19, 25]. Talking to someone about their feelings provided the caregivers with relief [18] and, in some cases, helped them better understand the diagnosis and management of cancer from the nurses, as shown in a study in China [27].

Caregivers also reported losing their source of income due to the extended amount of time they needed to provide care to their children. In some cases, caregiving duties forced the caregivers to stop working, and in some cases, they were allowed to work due to their inability to meet their work requirements, a case reported in other studies [14, 28]. Losing a source of income has a knock-on effect, especially since cancer care is costly and requires frequent hospitalisation and significant resources to foot bills, such as diagnostic tests, medicines and care, including the cost of transport and food [29]. This situation, the caregivers noted, is worsened by the limited coverage of health insurance and stockouts of chemotherapy medicines, resulting in partial or delayed care of the child or costly services and medicines from private health providers, which is reflected in findings in other studies [24, 30, 31].

Children with cancer, especially young children, fully depend on their parents for care and support, resulting in a significantly increased burden of care. The increased care burden affects not only the caregiver but also the people around the child and caregiver, including siblings, spouses, and immediate and extended family members. In our study, caregiving affected family dynamics, with the siblings of the child with cancer sometimes feeling abandoned, with all the attention being given to the sick child and the father or other family members having to take care of the siblings [13–15]. In addition to feeling overlooked and neglected [32], the siblings also felt that the parents were withholding information from them as a way of protecting them, but this made the children distant from their sick siblings [33]. Similarly, studies have shown that prolonged periods of maternal absence lead to siblings feeling neglected [15]. In addition, caregiving affected family dynamics, with the mother spending most of her time in the hospital with the sick child, while the father or other family members took care of the children left at home [13–15].

In addition, the caregivers noted that they felt a sense of being socially isolated by their family members and community due to the increased care burden and need for support, financially and in taking care of the sick child, their siblings or both, which was also reported in Zambia [26]. These feelings sometimes result in some parents/caregivers experiencing social stigma, alienation, and loneliness [16]. Cancer is a chronic illness and is costly to manage, which can lead people to pull away from their families directly or indirectly due to the depletion of resources and being overly dependent on other people for either time or monetary aid.

Importantly, caregiving affected the caregivers' marriages, with some reporting cases of separation, increased conflict, and neglect in their marriages. This highlights that while a family could be a source of support during caregiving, it is also likely to contribute to increased psychological and social issues. This calls for a holistic approach in the care of children with cancer with increased family involvement from diagnosis and a plan of action for the provision of care to a child to avoid burdening a single individual but also helping in addressing questions that the family and friends may have including demystifying the cancer diagnosis [34, 35].

In the transactional model of stress and coping, it is emphasised that when faced with stress, individuals try to identify ways that will aid in coping with their stress or try to adapt to the stressful environment [20]. In our study, some of the caregivers turned to churches and prayers as their source of strength, similar to findings in Nigeria [36]. and Malawi [37], where caregivers found solace when praying [18]. We infer that when caregivers are faced with situations that are beyond their control, they may turn to a supreme being[turn to their spirituality] for answers and comfort.

Moreover, caregivers sought and received moral and emotional support from their family members despite sometimes enduring segregation from them, a coping strategy reported in other settings [18, 19, 38] resulting in strengthened bonds in the family [19]. In one study in the United States, aunts, uncles, friends, and even teammates from the child's volleyball team helped in caring for the child [18]. , highlighting the critical importance of having a supportive community around the sick child and the caregivers. Our study revealed that some caregivers opted to talk about and share their worries with others.

Strengths and limitations

Our study was conducted among caregivers of children with cancer receiving treatment at a national referral hospital in Kenya, which allowed for the inclusion of a diverse set of caregivers from different regions in the country, making the results transferable to similar settings. However, the transferability of the findings is only possible for caregivers seeking services at public hospitals and for low- to middle-income populations. The study findings yielded insight that can be used to develop structures that can support caregivers during the caring period for children with cancer.

Conclusion

Our findings can aid in understanding the challenges experienced by the caregivers of children with cancer, which include financial, psychological, treatment-related, and social isolation challenges. The coping strategies applied during the caring process included the use of prayers, crying, and seeking help from professionals, family members, the community, social workers, and friends. Healthcare providers should be vigilant in helping caregivers identify positive coping strategies to better care for their children.

Abbreviations

FGD	Focus Group Discussion
NHIF	National Health Insurance Fund

Supplementary Information

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Supplementary Material 1

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We acknowledge the contributions of all the study participants—children, parents, and caregivers.

Author contributions

DVWM conceptualized the study. DVWM, AKM, JM and SO contributed to the study design. DVWM and SO collected and analyzed the data. DVWM and SMG drafted the manuscript. AKM, JM, SO and SMG reviewed and provided substantial contributions to the manuscript. All authors reviewed and approved the manuscript.

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Data availability

The datasets generated and/or analysed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Kenyatta National Hospital/University of Nairobi Institutional Ethics and Research Board (Ref: P391/04/2023), and the National Commission for Science Technology and Innovation (Ref: P-23-30490), and permission was obtained from the paediatric oncology department of the study hospital. All participants who agreed to participate provided written informed consent before the focus groups, and each participant was provided a code to anonymise their identity. The publication of anonymous responses was also explicitly mentioned during the informed consent process. The researchers offered appropriate compensation for participants during this study. The interviews were discontinued if any participant showed signs of fatigue, physical discomfort, or psychological distress, and appropriate management was provided if needed.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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