Palliative and Supportive Care

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Original Article

Cite this article: Onyeka T *et al.* (2024) In-hospital psychoeducation for family caregivers of Nigerian children with cancer (The RESCUE Study). *Palliative and Supportive Care* **22**(6), 1844–1855. https://doi.org/10.1017/S1478951524000178

Received: 22 January 2023
Revised: 9 November 2023
Accepted: 24 January 2024

Keywords:
Informal caregivers; childhood cancer; palliative care; in-hospital psychoeducation; Nigeria

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In-hospital psychoeducation for family caregivers of Nigerian children with cancer (The RESCUE Study)

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Abstract

Objectives. High levels of caregiver burden (CB) are experienced by informal caregivers of pediatric patients with cancer. There is increasing evidence highlighting the extent of CB across sub-Saharan African countries, although there remains lack of interventions that target improvements in their experience. This study aimed to determine the impact of a structured psychoeducation program on caregivers' outcomes relating to preparedness to provide care, burden of caregiving, and quality of life (QoL).

Methods. This quasi-experimental (pre-and-posttest) design, involved family caregivers of children on admission for cancer treatment in 4 Nigerian tertiary hospitals. Eligible participants received 2 structured, psychoeducational training sessions delivered by a multidisciplinary oncology team, focusing on the management of patients' condition, spiritual care, self-care, and support.

Results. Subjects were mainly female (79.5%) and mostly mothers to children undergoing cancer treatment (74.7%). Commonest cancer type was acute lymphoblastic leukemia (23.9%) with evidence of metastatic disease found in 9.6% of children. Significant improvements were observed between pre- and posttest for unmet needs ($z = -9.3$; $p < 0.001$), preparedness for caregiving in palliative care (PCPC) ($z = -7.0$; $p < 0.001$), and overall QoL ($z = -7.3$; $p < 0.001$). A significant reduction in CB was also reported ($z = -8.7$; $p < 0.001$).

Significance of results. This psychoeducational intervention (PEI) resulted in significant improvements in unmet needs, CB and significant improvements in PCPC. However, a reduction in QoL of the family caregivers was also observed. Findings from this study should encourage the use of well-crafted PEIs, delivered within hospital settings to promote improvements in outcomes for informal caregivers of hospitalized children suffering from cancer, in an African context. Further intervention development is required to better understand intervention components influencing changes in outcomes, while exploring feasibility testing and adaptation to similar settings in Nigeria and within Africa.

Introduction

Pediatric cancer is a global problem with worse repercussions in resource-poor settings, where it is rising to become the third commonest cause of childhood death (White et al. 2013). Despite 90% of children with cancer residing in low-income and middle-income countries (LMICs), data in these settings are scarce (Bhakta et al. 2019). In the context of health care in African countries, parents and guardians are critical instruments to ensure the delivery of person-centered care (Basu et al. 2014). Caregivers in pediatric cancer care have multiple responsibilities, including bearing financial burdens, assisting with daily activities, making important decisions with oncologists, and providing emotional support (Söderbäck and Christensson 2008; Van Ryn et al. 2011). However, if informal caregivers experience a high degree of burden, the needs of the patients they care for are likely to go unmet (Bekui et al. 2020; Hudson and Aranda 2014). The financial and socioeconomic impact of cancer can negatively affect the well-being of parents, potentially leading to treatment abandonment for their child (Arora et al. 2007). Additionally, caregivers often experience fatigue, anxiety, depression, grief, and loss associated with the impending death of their charge (Bekui et al. 2020; Lim et al. 2017). Limited studies on informal caregiving for people with cancer from African countries, particularly focusing on supporting children, exist (Akpan-Idiok and Anarado 2014; Söderbäck and Christensson 2008). In Nigeria, the provision of pediatric home and hospice care is lacking, with only 5 out of 10 listed institutions and organizations indicating services for children with palliative care needs (IAHPC 2022). The majority of informal caregivers in the country are women (Söderbäck and Christensson 2008) who face societal and trado-cultural expectations to be homemakers. These caregivers often have other children at home and may have to prematurely wean off an infant to accompany their sick child for hospitalization. Moreover, the traditional extended family systems that once provided support during caregiving crises in Nigeria are diminishing due to modernization and urbanization, leaving informal caregivers isolated and stranded (Aniche 2017; Imouokhome Obayan 2007). There is therefore the need for increased support for informal caregivers in hospital settings in Nigeria.

Informal caregivers of children often have limited knowledge about disease conditions, can be poorly prepared for all that is involved in caregiving in the hospital setting, and may face pressures from the extended family to abandon treatments (Söderbäck and Christensson 2008). For informal caregivers in pediatric oncology, children often present with advanced disease with a consequent higher demand on scarce financial resources of these caregivers (Adejoh et al. 2021). Literature from across sub-Saharan Africa (SSA) indicates that following admission, the hospital setting itself can present multiple challenges for informal caregivers, including being required to sleep on the ground outside hospital buildings, exposure to mosquitoes and hospital-acquired infections, overcrowding and a lack of kitchen facilities and hygienic public toilets and facilities. Furthermore, informal caregivers report sleep deprivation, fatigue, emotional distress, and hunger, which create an increased vulnerability to succumbing to ill-health (Mwangi et al. 2008). A systematic review of interventions for cancer caregivers has identified interventions to include psychoeducation, problem-solving/skills-building interventions, supportive therapy, family/couples therapy, cognitive-behavioral therapy, interpersonal therapy, complementary and alternative medicine interventions, and existential therapy (Applebaum and Breitbart 2013). A recent review highlighted that structured information provided to informal caregivers by health-care professionals can reduce their anxiety, increase their quality of life (QoL), reduce caregiver burden (CB) and increase their knowledge of patient's illness (Hudson et al. 2012; Jadalla et al. 2020). Interventions like this may provide a means for health-care workers to support the numerous needs of both pediatric patients and their informal caregivers. Psychoeducational interventions (PEIs), which may vary in format in terms of disease-treatment format, delivery and timing, have been known to improve caregiver preparedness for caregiving (Holm et al. 2016). They are known to promote knowledge sharing, and a sense of belonging and enhance social relationships between caregivers (Cipolletta et al. 2018, 2019). They are also important to alleviate issues such as anxiety and depression that may undermine the caregiver's ability to render physical and psychological support to the ailing child (Malangwa and Mangi 2022). PEIs are known to offer a therapeutic microcosmos for caregivers with like experiences to relate with each other and not run the risk of being misunderstood or alienated from society as a result of the cancer diagnosis of their children (Cipolletta et al. 2019). In addition, psychoeducation has been known to significantly increase the coping skills and QoL of caregivers of patients receiving palliative care (Çetin and Nehir 2020). A structured PEI is not only warranted but also critical for informal caregivers of children with cancer in Nigeria due to several reasons. Many informal caregivers may lack knowledge about childhood cancer, its treatment options, and the associated challenges. A structured PEI can provide them with comprehensive information about the disease, including its causes, symptoms, treatment modalities, and potential side effects. This knowledge equips caregivers with the necessary understanding to provide appropriate care and support to the child. In Nigeria, informal caregivers of children with cancer may encounter difficulties navigating the health-care system, accessing appropriate resources, or advocating for their child's needs. A structured PEI can empower caregivers by educating them about their rights, entitlements, and available resources. Hence, this study sought to determine the impact of a structured psychoeducation intervention on the unmet needs, preparedness to care, CB, and QoL of informal caregivers of hospitalized pediatric patients with cancer in Nigeria.

Methods

Study design

This was a quasi-experimental (pre-and-posttest) design which sought to implement a psychoeducation intervention for informal caregivers of hospitalized Nigerian children with cancer. While this study design presents threats to internal validity, it represents a pragmatic approach by the research team to gather initial evidence of any potential impact arising from the PEI. The relative simplicity of the study design when compared to other nonrandomized, pre-post intervention studies enabled delivery of the study across multiple sites, all with limited research infrastructure.

Setting

This study involved 4 tertiary teaching hospitals in Nigeria that provide pediatric oncology services and were selected based on criteria such as being the oldest institution in their region, having a university affiliation, and the willingness of investigators at the site to participate. The goal was to select at least 1 institution from each geopolitical region for representation. In Nigeria, there are 20 Federal Teaching Hospitals in existence and not all have established pediatric oncology services. Using a multistage sampling technique, study sites were selected thus: In the first stage, 12 institutions were stratified into 2 larger groups of 6 each from the Southern and Northern regions of Nigeria. In the second stage, each region was further stratified into 3 smaller groups representing 3 geopolitical zones per region (i.e., 3 groups in the Southern region and 3 groups in the Northern region). In the third stage, the process of balloting was used to select 1 institution from each small group as described in the second stage. A total of 6 institutions were selected across the 6 geopolitical zones of the country (i.e., 3 Northern and 3 Southern institutions). However, 2 institutions (1 Southern and 1 Northern) did not eventually participate in the study, citing lack of interest and insurgency-related declines in patient load respectively.

Inclusion and exclusion criteria

Typically, most pediatric inpatients in Nigeria are required to have at least 1 member of their family as an on-site caregiver. This study's eligible participants were informal caregivers of pediatric inpatients in Nigeria who are typically required to have at least 1 family member as an on-site caregiver. At study enrolment, the main caregiver was identified as the one who accompanied the patient for the admission and was responsible for caring for the child during the hospitalization. However, in a few cases, multiple caregivers were involved due to social circumstances. Eligible participants were 18 years of age or older, family members of the pediatric patient, those who provided physical, emotional, or other support to a child with cancer who was admitted to a pediatric ward for cancer management; and those who had a family relative who could ensure continuity of support for the child patient during the study. Informal caregivers were excluded if they were unable to give consent or could not provide a family relative during the study.

Sample size estimation/sample selection

In computing the required minimum sample size, the formula for comparison of the mean of 2 groups, $N = 2[(Z\alpha + Z\beta)\sigma\ /C]2$, was used, where $Z\alpha$ = standard normal deviation for $\alpha = 1.96$; $Z\beta$ = standard normal deviation for $\beta = 0.84$; *Ϭ = population standard deviation (this was assumed as there are no previous similar studies done) = 50; and C = difference in QoL between the group's pre- and post-intervention = 30. A minimum of 174 participants were required for the study and after adjusting for attrition (5%), and a total of 180 was obtained for the sample size (see Figure 1). In the final stage, participants were recruited consecutively until the required sample size was achieved per center. They were approached on the wards and during their attendance at the pediatric outpatient clinic, and those who gave their consent were enrolled in the study.

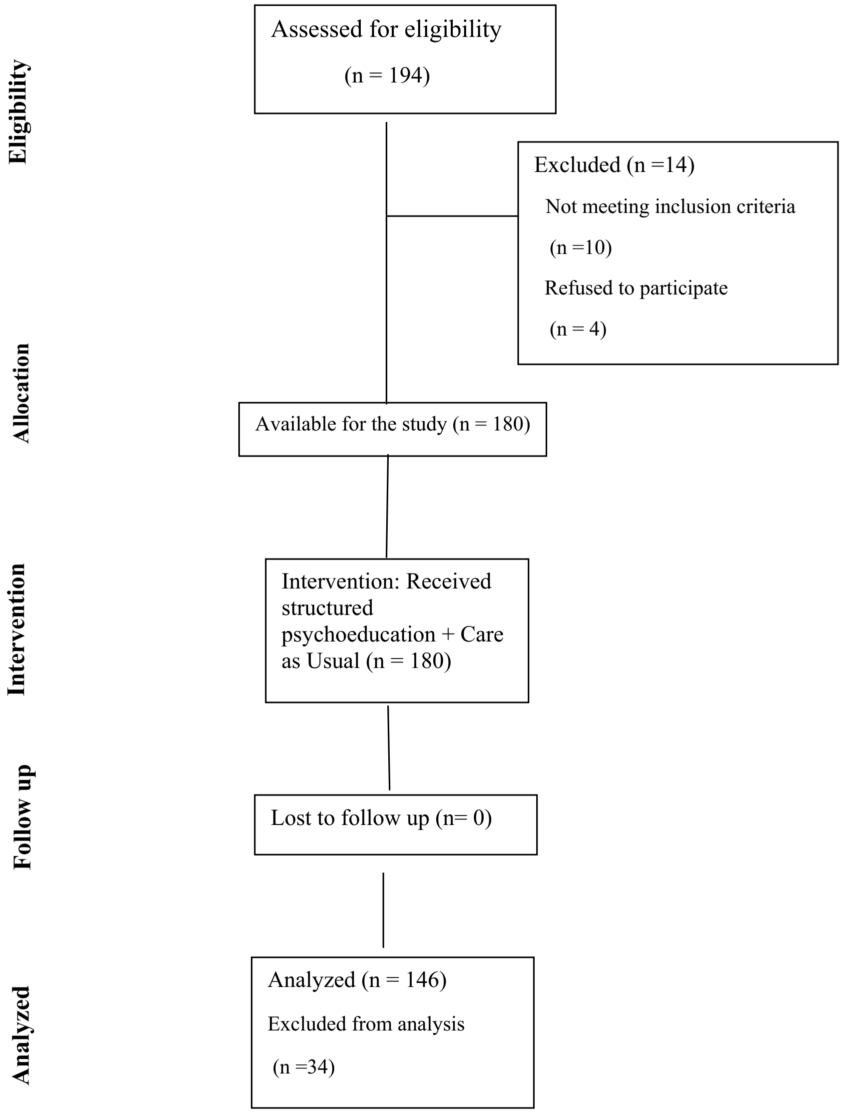

Figure 1. Flow diagram of study.

Intervention description

Two sessions were conducted involving a range of professionals to develop the toolkit based at the Principal Investigator's study site. Professionals provided a range of perspectives and included palliative care physicians (i.e., direct involvement in the care and management of children with cancer) ($n = 2$), pediatric oncologists (i.e., have direct clinical oversight and governance of children with cancer) ($n = 3$), psycho-oncologists (i.e., to provide insights and reflections on psychosocial aspects of care) ($n = 2$), pediatric ward nurses (i.e., due to their daily interaction with children with cancer and their caregivers) ($n = 4$), and radiation oncologists (i.e., to incorporate their experiences with radiation side effects in children during and after treatment) ($n = 3$). The toolkit comprised content developed and presented in Microsoft PowerPoint in English which was subsequently sent to co-investigators at the other 3 study sites for their input. This was used as the basis for the psychoeducation intervention. The development of the intervention took into consideration the theoretical framework of Andershed and Ternestedt (2001). This theory is based on the notion that a positive care culture of the patient can positively influence caregivers' possibilities for involvement in their care (Andershed and Ternestedt 2001) and explicates the involvement and needs of caregivers involved in palliative care (Holm et al. 2017). It classifies the involvement of family members in the care of a loved one into "knowing" (receiving knowledge of the ailment), "being" (being present and willing to help out in the care) and "doing" (actual physical involvement in the care). Activities to reflect these 3 concepts were included in the toolkit. In addition to involving professionals in the toolkit development, a group of informal caregivers of pediatric patients with cancer (6 females and 2 males aged between 21 and 40 years; $n = 8$) who were attending the pediatric oncology outpatient clinic with their children were engaged. The lead author used qualitative in-depth interviews to develop the intervention materials. The interviews covered topics such as the caregivers' needs, personal knowledge of childhood cancer and areas of interest, and feedback on the intervention materials. Interviews were audio recorded, transcribed, and reviewed by 2 of the investigators (TO and JO). Transcripts were analyzed using a simplified deductive content analysis approach (Krippendorff 2013), identifying units of analysis relating caregiver needs, informational needs, and appraisal of toolkit content, creating themes to link the underlying concepts together in categories. This enabled the team (TO and JO) to organize and present data relating to caregiver needs, knowledge gaps and feedback, and suggestions on how to improve the intervention content (e.g., content that was difficult to understand, language used around cancer and caregiver roles). Feedback from the caregiver group was used to refine the content and presentation of materials and verify that identified needs were addressed by materials forming the intervention. Teams at each site shared notes and recordings made during piloting the use of the toolkit with the principal investigator and with each other before the intervention, to ensure uniformity in the use of and delivery of the intervention and ultimately fidelity. The refined psychoeducation intervention has a supportive and educational component covering 4 domains: education of the informal caregiver on patients' condition and simple care of the patient, spiritual care, self-care, and support group strategies.

The content of the tool-kit which consisted largely of audio-visual presentations included content on understanding what childhood cancer is, its symptoms and signs, tests/laboratory investigations, treatment options and treatment side-effects, non-health problems of childhood cancer, talking with the child and siblings about cancer, helping child and siblings cope, survivorship and follow-up care, what to do when treatment fails, the impact of caring for someone with the illness, positive aspects of caring, how to reduce caregiver stress, the importance of respite breaks, health and well-being of the caregiver (i.e., physical, emotional spiritual and mental health, including the value of sleep, simple exercise and relaxation methods), learning about supporting each other, the role of faith in illness (prayer, meditation, use of holy books and articles such as prayer beads), the need for support (family, friends, other caregivers), and the role of cancer support groups. The final toolkit (Table 1) was translated by medical translators into Hausa, Yoruba, and Igbo languages for ease of administration to non-English-speaking participants and was used in all the other study centers to ensure validity and consistency of the results obtained from the study.

The study required caregivers to attend two 2-hour sessions, 1 week apart, in groups of 5–6, in a designated area within the hospital. At each site, a pediatric oncologist, psychiatrist, palliative care physician or oncology nurse delivered the intervention through didactic lectures, group activities, and Q&A. The sessions covered spiritual care, self-care, and other aspects, and included faith-based songs, prayers and meditation, and caregivers interacting with each other to build support networks. The study also provided improved living spaces and amenities for caregivers and held team meetings every 2 months to review progress.

Table 1. Contents of the toolkit

Week	Topic	Content
1	Childhood cancer education – Part 1	Learn what cancer is; Understand what causes it; Find out how to tell if a child suffers from cancer; Tests that can be done before treatment; Treatment side effects
	Self-care – Part 1	Impact of caring for someone with an illness; Positive aspects of caring; How to reduce caregiver stress; Importance of respite break
	Spiritual care	Prayer and meditation
	Support group strategies 1	Making friends of co-caregivers; Discussions on feelings, concerns and attitudes in a caring atmosphere; Talk openly about your feelings, receive practical advice; Sharing resources and contacts; Understanding and describing the caregiver experience
2	Childhood cancer education – Part 2	Non-health problems of childhood cancer; Talking with your child; How to cope as a parent; Helping child to cope; Helping brothers and sisters cope; Survivorship and follow-up care; What to do when treatments fail
	Self-care – Part 2	Learn about health and well-being of the caregiver (physical health, emotional/mental/spiritual); Discovering the value of sleep; Learning simple exercise and relaxation methods; The Food–Mood Connection; Learning about supporting each other.
	Spiritual care	Prayer and meditation
	Support group strategies – Part 2	Break-up sessions for discussion; each group moderated over by a social worker, nurse, or counselor; Collection and exchange of names, phone numbers, and contact addresses by each member of the group at end of activity.

Data collection and measurement

Diagnostic interviews (i.e., structured conversations between a health-care provider and a patient to gather information and make a medical diagnosis) were conducted by the pediatric oncologist with patients, and diagnosis was established via a combination of medical history, examination, and histological findings. Caregivers were informed about the study and completed sociodemographic and study questionnaires if they met the inclusion criteria. Participants were determined to be literate or illiterate through assessment of basic literacy done by checking their ability to recognize letters, words, or numbers. For literate participants, the questionnaires were self-administered, but for low-literacy and nonliterate participants, they were administered by a trained research assistant. Patient characteristics were also obtained from case notes. Baseline assessment of participants involved completion of the following measures: Caregiver Quality of Life Index-Cancer (CQoLC) scale (Weitzner et al. 1999), Zarit Burden Interview (ZBI)/Caregiver Burden Scale (Yu et al. 2020), Preparedness for Caregiving Scale in Palliative Care (Henriksson et al. 2015), and Needs Assessment of Family Caregivers-Cancer (NAFC-C) questionnaire (Yang et al. 2020) (Table 2). This was followed by the completion of all questionnaires post-intervention.

Data analysis

Data were analyzed using the International Business Machine-Statistical Package for the Social Sciences (IBM-SPSS©) version 20. Descriptive statistics were used to describe demographics and clinical characteristics while a comparison of pre-intervention and post-intervention outcome measure scores obtained from participants following administration of the CQoLC scale, ZBI, and NAFC-C questionnaire was performed using the Wilcoxon-signed ranked test. A multiple linear regression analysis was conducted to evaluate the prediction of QoL, CB, preparedness for caregiving in palliative care and unmet needs from sociodemographic characteristics (including age, biological sex, and ethnicity). A p-value <0.05 was considered statistically significant.

Table 2. Overview of questionnaires used to gather pre- and post-intervention measures of participants

Questionnaire name	Details of the questionnaire
Zarit burden Inyerview (ZBI)/ Caregiver Burden Scale questionnaire	This questionnaire developed to assess caregiver burden in relatives of patients with chronic mental illness is a 22-item instrument that includes factors most frequently mentioned by caregivers as problem areas in providing care for patients with mental disorders. It has a possible score of 0 − 88 depending on caregiver responses. Responses are rated from 0 to 4, based on level of distress. It has good internal consistency (Cronbach's $\alpha = 0.93$). It has been validated in several studies in Nigeria
Caregiver Quality of Life Index-Cancer (CQOLC) Scale	A 35-item questionnaire used to evaluate physical, emotional, spiritual, financial and social quality of life (QoL) of caregivers over a prior 7-day period. It assesses both negative and positive aspects of caregiving. Responses are rated on a 5-point Likert scale giving a total score of 140. The higher the score, the better the QOL. It is known to have good reliability and internal consistency (Cronbach's $\alpha = 0.91$) and has been validated in some oncology inpatient settings in Africa.
Preparedness for Caregiving Scale in Palliative Care (PCS-PC) Scale	This measures readiness of caregiver to provide care during palliative care phase of a patient's management. Responses are rated on a 5-point Likert scale and a total score of between 0 and 32 is possible with higher scores indicating better perceived readiness for caregiving in palliative care. It has good internal consistency (Cronbach's $\alpha > 0.89$).
Needs Assessment of Family Caregivers-Cancer (NAFC-C) Scale	This scale is based on the Need Fulfillment Theory pioneered by Abraham Maslow which says that the physiological and psychological needs of individuals which need fulfillment can be determined and motivated by how the individual thinks, acts or responds. Hence, if a very important need of a caregiver is satisfactorily met, the caregiver's level of fulfillment is equally higher. But when a very important caregiver need remains unmet, the sense of fulfillment is low or non-existent. With 27 items reflecting 4 domains (psychosocial (9 items), medical (7 items), financial (3 items), and daily activity (8 items) unmet needs.), it has the ability to predict demographic characteristics of caregivers whose needs are more or less likely to be met. Using a 5-point Likert scale (0 = not at all, 4 = extremely), caregivers are expected to rate each of the 27 need items on how important the need has been for them during the past 4 weeks, and on how satisfied they have been with the fulfillment of the need during the past 4 weeks. In the scale, the satisfaction rating is reverse-coded and the need item is scored by multiplying the importance rating by the reversed satisfaction rating to give scores ranging from 0 to 16. The higher the score the higher the unfulfilled need. It has a good validity and satisfactory internal consistency ($0.56 < \alpha s < 0.86$) and has been used in several populations with good success.

Results

Demographic and clinical characteristics

This study recruited 180 informal caregivers of children with cancer from 4 different study sites between March 2019 and April 2020. A total of 146 participants completed the intervention (see Figure 1) and were mostly female (79.5%), from nuclear families (89%), mothers of the sick child (74.7%), had at least 6 years of education (52.7%), unemployed (77.4%), and a mean monthly household income of ₦20,000 (₦: Naira), which is currently equivalent to $42. Table 3 shows the sociodemographic characteristics of the children and their family caregivers. The age range of children was 6 months to 17 years. A greater proportion were male (68.5%), with the commonest cancer types reported being acute lymphoblastic leukemia (ALL) (23.9%) and osteosarcoma (22.5%) while the least reported cancer type was Burkitt's lymphoma (5.1%). Evidence of metastatic disease was found in 9.6% of all children, while the number of children with active disease and receiving treatment (38.4%) was similar to the number of children who were in remission and had no evidence of the disease (38.4%). Most children had no comorbidities (88.4%).

Outcome measures

For all participants who completed all components of the structured cancer education on caregiver QoL (Table 4), participants' overall QoL was significantly lower at the end of the intervention (pre-intervention overall mean score = 96.1; $p< 0.001$ versus post-intervention overall mean score = 63.2; $p< 0.001$) and participants' QoL across all domains was also significantly lower. However, preparedness for caregiving in palliative care (PCPC) was significantly increased ($z = -7.3$; ($p< 0.001$) and CB significantly reduced ($z = -8.7; p< 0.001$) with good-to-excellent effect size (−0.8[−1.6 to −0.1] and 1.3[0.5 to 2.2] respectively). Before the intervention, participants reported unmet needs in the psychosocial, medical, financial and activities of daily living (ADL) domains with the highest unmet need being in the psychosocial (Mean(SD) = 5.5(1.5)) and ADL domains (Mean(SD) = 5.5(1.6)). In exploring the effect of the intervention on caregiver unmet needs, there was a significant overall decrease in unmet needs as well as significant decreases in unmet needs in each domain ($p< 0.001$).

In examining the relationship between sociodemographic/clinical variables and outcome variables post-intervention (Table 5), the multiple linear regression analysis found ethnicity to be a significant predictor of QoL. Post-intervention, there was an overall reduction in QoL, with Hausa/Fulani caregivers having significantly better QoL than Yoruba ($p < 0.001$) and Igbo caregivers with significantly better QoL than Yoruba caregivers ($p = 0.01$). Being employed was a significant predictor of the reduction in 3 of 4 domains of unmet needs [psychosocial needs ($p= 0.005$), medical needs ($p= 0.003$), and financial needs ($p= 0.004$)]. Caregivers of Hausa/Fulani ethnicity had significantly lower PCPC scores post-intervention when compared to those of Yoruba ethnicity ($p = 0.004$), indicating a higher level of preparedness of the latter. Being of younger age ($\beta = -0.21$, $t = -2.48$, $p < 0.001$) and pre-intervention level of preparedness ($\beta = 0.30$, $t = 3.57$, p = 0.001) were significant predictors of higher scores of PCPC post-intervention. High pre-intervention CB score was

Table 3. Sociodemographic and clinical characteristics of children and family caregivers

Variables	*n* (%)	Mean ± SD Median (IQR)
Children ($N = 146$)		
Age (in years)		7.6 (4.9); Range: 6 months–17 years
Gender		
Male	100 (68.5)	
Female	46 (31.5)	
Cancer type		
ALL	33 (23.9)	
Burkitt lymphoma	7 (5.1)	
Hodgkin's lymphoma	8 (5.8)	
Non- Hodgkin's lymphoma	10 (7.2)	
Renal cell carcinoma	21 (15.2)	
Osteosarcoma	31 (22.5)	
Brain tumor	20 (14.5)	
Rhabdomyosarcoma	8 (5.8)	
Disease Status		
NED, treatment complete	1 (0.7)	
NED, remission, active treatment	56 (38.4)	
Active disease, active treatment	56 (38.4)	
Metastatic disease	14 (9.6)	
Unclassified	14 (13.0)	
Presence of Comorbidities		
Yes	17 (11.6)	
No	129 (88.4)	
Family caregivers ($N = 146$)		
Age (in years)		37.0 (9.9); Range: 19–70 years
Gender		
Male	30 (20.5)	
Female	116 (79.5)	
Level of Education		
No formal	12 (8.2)	
Primary	57 (39.0)	
Secondary	47 (32.2)	
Tertiary	30 (20.5)	
Employment Status		
Employed	33 (22.6)	
Unemployed	113 (77.4)	
Religious Affiliation		
Christians	74 (50.7)	
Muslims	72 (49.3)	
Ethnicity		
Hausa	53 (36.3)	
Yoruba	22 (15.1)	
Igbo	30 (20.5)	
Others	41 (28.1)	
Relationship with the child		
Father	15 (10.3)	
Mother	109 (74.7)	
Sibling	6 (4.1)	
[a]Others	16 (11.0)	
Income per month (in ₦)	20,000 (45,000)	

[a] "Others" denotes extended family relations such as uncle, aunt, cousin, grandparent and hired helper.

a significant predictor of high scores post-intervention ($\beta = 0.32$, $t = 3.00$, $p = 0.003$) (Table 6).

Discussion

The main findings from this study are that informal caregivers who were mostly females and mothers reported significant improvements in unmet needs, and significant improvements in PCPC but a significant reduction in their QoL at the end of the intervention. This highlights that well-tailored interventions for informal caregivers in hospitals located in SSA are feasible and may be able to contribute positive improvements to the support provided to and experience of caregivers during the hospitalization phase of their children. This study explicates the advantages of group psychoeducation in cancer care and palliative care (Cipolletta et al. 2019; Dionne-Odom et al. 2019; Mahendran et al. 2017; Tang et al. 2020). With this research, the psychoeducational intervention appeared to significantly increase PCPC and significantly reduce CB and unmet needs. This is in keeping with similar studies conducted with informal caregivers of cancer patients receiving palliative care both at home and in the hospital (Harding et al. 2012; Henriksson et al. 2013; Hudson et al. 2009). While it also affirms the assertion that informal caregivers in cancer and palliative care encounter multifaceted responsibilities and are often encumbered by them (Holm et al. 2017; Seliner et al. 2016), this research highlights the high unmet needs of study participants prior to the intervention. This underscores the need for pediatric oncologists to account for the needs of informal caregivers and provide them with adequate support during the management of hospitalized pediatric patients with cancer.

Findings from this study echo findings from previous studies that emphasize the need to improve the experience of caregivers

Table 4. Wilcoxon test to explore the effect of structured cancer education on caregivers' quality of life

Variables(CQoLC)-Scale	Mean (SD)	Median (IQR)	*z*-stat	*p*-value	Effect size (95%CI)	NR	PR	Ties
Pre-int Overall	96.1 (19.9)	96.0 (29.0)						
Post-int Overall	63.2 (22.4)	72.0 (44.0)	−9.3	<0.001	1.6 (−1.2 to 4.3)	115	11	1
Pre-int BD	25.0 (9.0)	27.0 (15.00)		<0.001				
Post-int BD	16.1 (7.5)	16.0 (12.0)	−9.0		1.0 (−0.4 to 2.4)	118	16	4
Pre-int DD	19.3 (4.8)	21.0 (6.0)						
Post- int DD	12.4 (5.1)	13.0 (9.0)	−8.8*	<0.001	1.4 (0.8 to 2.0)	125	12	1
Pre- int PAD	20.5 (4.6)	22.0 (8.00)						
Post- int PAD	15.8 (6.7)	16.0(13.0)	−6.8*	<0.001	0.8 (0.2 to 1.5)	99	33	9
Pre- int FCD	8.4 (2.6)	9.0 (3.0)						
Post- int FCD	5.7 (2.4)	6.0 (4.0)	−8.0*	<0.001	1.1 (0.8 to 1.4)	101	14	19

z = Wilcoxon-signed ranked test; CQoLS-Scale = Caregiver Quality of Life Index-Cancer Scale; int = intervention; BD = burden domain; DD = disruptiveness domain; PAD = positive adaptation domain; FCD = financial concern domain; PR = positive ranks, NR = negative ranks.
*connotes statistically significant.

Table 5. Relationship between sociodemographic and clinical variables with outcome variables post intervention

Variables	CBMedian (IQR)	PCPCMedian (IQR)	QoLMedian (IQR)	PSNMedian (IQR)	MNMedian (IQR)	FNMedian (IQR)	DANMedian (IQR)
Gender							
Male	12.0 (8.5)	31.5 (1.0)	34.0 (46.8)	3.5 (1.7)	2.6 (1.3)	1.4 (0.6)	3.4 (1.5)
Female	14.0 (5.8)	30.0 (6.0)	73.0 (46.8)	4.8 (2.0)	3.9 (1.6)	1.9 (0.8)	4.6 (0.9)
	$p = 0.09$*	$p = 0.59$*	$p = 0.05$*	$p = 0.006$*	$p = 0.007$*	$p = 0.004$*	$p = 0.006$*
Employment							
Employed	12.5 (4.5)	31.0 (3.3)	57.0 (48.3)	3.5 (1.5)	2.7 (1.2)	1.3 (0.6)	3.6 (1.5)
Unemployed	14.0 (6.3)	30.5 (6.0)	73.0 (47.3)	5.0 (1.3)	4.0 (1.2)	1.9 (0.7)	4.6 (0.9)
	$p = 0.22$*	$p = 0.03$*	$p = 0.39$*	$p < 0.001$*	$p < 0.001$*	$p < 0.001$*	$p = 0.001$*
CR							
Nuclear	14.0 (6.0)	31.0 (6.0)	73.0 (47.8)	4.5 (2.2)	3.5 (1.9)	1.7 (0.6)	4.3 (1.6)
Extended	12.0 (5.5)	31.0 (3.0)	34.0 (27.5)	4.5 (1.9)	3.5 (1.8)	1.5 (6.0)	4.0 (2.0)
	$p = 0.75$*	$p= 0.16$*	$p = 0.02$*	$p = 0.27$*	$p = 0.27$*	$p = 0.54$*	$p = 0.43$*
Ethnicity							
Hausa/Fulani	14.0 (5.0)	27.0 (9.0)	79.0 (11.0)	5.6 (0.3)	4.4 (0.6)	1.9 (0.9)	4.9 (0.3)
Igbo	13.0 (6.0)	31.0 (4.3)	57.0 (54.3)	3.3 (1.5)	2.5 (1.0)	1.2 (0.6)	3.1 (1.5)
Yoruba	11.0 (6.5)	31.0 (1.0)	33.5 (4.5)	4.5 (1.7)	3.4 (1.3)	1.5 (0.6)	4.0 (1.5)
Others	14.0 (12.0)	30.0 (5.0)	71.0 (46.5)	4.5 (1.8)	3.5 (2.4)	1.6 (1.5)	4.6 (1.8)
	$p = 0.02$**	$p = 0.001$**	$p < 0.001$**	$p < 0.001$**	$p < 0.001$**	$p< 0.001$**	$p < 0.001$**
Disease Status							
RAT	14.5 (6.5)	28.0 (6.3)	79.0 (69.0)	5.6 (0.7)	4.4 (1.1)	1.9 (1.1)	4.9 (1.0)
ADAT	12.0 (4.0)	31.0 (3.0)	33.0 (6.0)	4.3 (1.7)	3.0 (1.3)	1.5 (0.6)	4.0 (1.5)
MD	11.0 (11.5)	32.0 (1.3)	34.0 (18.6)	4.5 (1.8)	3.4 (1.1)	1.5 (0.3)	4.0 (1.2)
	$p = 0.11$**	$p = 0.30$**	$p < 0.001$**	$p < 0.001$**	$p < 0.001$**	$p < 0.001$**	$p < 0.001$**

PCPC = preparedness for care in palliative care; CB = caregiver burden; PSN = psychosocial needs; MN = medical needs; FN = financial needs; DAN = daily activities needs; QoL = quality of life; RAT = remission, in active treatment; ADAT = active disease, active treatment; MD = metastatic disease; CR = caregiver relationship with the child.
*Mann–Whitney *U*-test; **Kruskal–Wallis test.

of people living with cancer, recommending the use of various forms of PEIs (Hudson et al. 2009; Hudson and Aranda 2014). An earlier meta-analysis by Northouse et al. (2010) detailed small to medium benefits of psychoeducational interventions on CB and QoL. In contrast to the study by Mollica et al. (2020) where younger caregivers experienced higher unmet needs related to caregiving skills, the younger caregivers in this study had significantly higher PCPC post-intervention, a finding that underscores the need for

Table 6. Sociodemographic predictors of quality of life, PCPC, unmet needs, and caregiver burden

	QoL	PCPC	CB	PSN	MN	FN	DAN
Predictors	β t-stat *p*-value	β t-stat *p*-value	β t-stat *p*-value	β t-stat *p*-value	β t-stat *p*-value	β t-stat *p*-value	β t-stat *p*-value
Age	0.15	−0.21	0.12	0.001	0.06	0.23	0.13
	1.82	−2.48	1.39	0.01	0.69	2.45	1.35
	0.07	<0.001	0.17	0.99	0.49	0.02	0.18
Gender	0.05	−0.15	0.06	0.09	0.07	0.05	0.07
	0.53	−1.64	0.64	0.86	0.65	0.52	0.60
	0.60	0.10	0.53	0.39	0.52	0.61	0.55
Ethnicity	−0.24	0.13	0.01	−0.10	−0.05	0.13	−0.06
	−2.57	1.39	0.13	−1.04	−0.49	1.25	−0.45
	0.01	0.17	0.90	0.30	0.63	0.22	0.65
Employment	−0.07	−0.13	−0.02	0.29	0.29	0.21	0.20
	−0.77	−1.43	−0.18	2.87	3.10	2.14	1.87
	0.44	0.16	0.86	0.005	0.003	0.04	0.07
CR	−0.18	0.07	0.01	−0.09	−0.13	−0.18	−0.13
	−1.93	0.68	0.14	−0.82	−1.32	−1.67	−1.08
	0.06	0.50	0.89	0.41	0.19	0.10	0.28
Pre-int PCPC	−0.02	0.30	−0.01	−0.12	−0.17	−0.05	−0.15
	−1.20	3.57	−0.09	−1.20	−2.06	−0.53	−1.57
	0.84	0.001	0.93	0.23	0.04	0.60	0.12
Pre-int CB	0.02	−0.04	0.32	0.15	0.17	0.18	0.16
	0.18	−0.40	3.00	1.35	1.63	1.66	1.52
	0.86	0.69	0.003	0.18	0.11	0.10	0.13
Pre-int QoL	0.26	0.13	0.09	0.17	0.26	0.28	0.19
	2.26	1.30	0.87	1.57	2.48	2.53	1.67
	0.01	0.20	0.39	0.12	0.02	0.01	0.10

B = standard coefficient; PCPC = preparedness for care in palliative care; CB = caregiver burden; PSN = psychosocial needs; MN = medical needs; FN = financial needs; DAN = daily activities needs; QoL = quality of life; CR = caregiver relationship with the child.

the implementation of this and similar interventions in pediatric palliative care and oncology practice. PEIs have been shown to consistently have the greatest benefits regarding the improvement of caregiver knowledge, self-help skills and attitudes toward disease and its treatment (Rosney et al. 2017). Interventions enlisting informal caregivers of ethnic minorities, and underserved populations and research to understand implementation in the context of LMICs have been sparse (Molassiotis and Wang 2022). This study provides novel insights relating to the latter, informing the feasibility of PEIs to address the needs of the informal caregiver.

Informal caregivers are greatly affected by the cancer management process that often includes multiple laboratory investigations, assorted cancer treatments with their associated side effects, care arrangements, work disruptions for the employed caregiver, coordination of appointments, and management of financial situation among other issues (Langegård et al. 2023; Molassiotis and Wang 2022; Mollica et al. 2020; Rosney et al. 2017; Zhou et al. 2022), all of which can negatively affect their QoL (Alptekin et al. 2010). However, while targeting numerous aspects of caregiver well-being, the educational intervention did not lead to improvements in QoL. A systematic review of psychosocial interventions compared with usual care, which was conducted in high-income countries for caregiver-patient dyads, showed minimal benefit for caregiver QoL during and after the intervention (Treanor et al. 2019). Also, issues relating to fear of child dying, treatment length, and unexpected treatment-related drawbacks experienced by the informal caregivers during hospitalization often produce anxiety and depression that negatively affects caregivers QoL (Carosella et al. 2018). We posit that since this PEI could not take care of multiple caregivers needs such as well-prepared meals, issues with funding cancer treatment, and coordinating the care of a sick child with the care of siblings and spouse at home, these factors may serve as stressors and hence possible catalysts for a reduction in QoL observed at end of the intervention. Thus, these unmet needs could be a reasonable justification for the revision of possible outcome measures in future evaluations. Mothers were the predominant primary caregivers in this study, a finding that compares with studies of family caregivers of hospitalized children in Mozambique (Söderbäck and Christensson 2008) and Tanzania (Mwangi et al. 2008) where mothers were largely involved in caregiving during hospital admission of their children. For many mothers, caring for such children represents a drastic change from the norm and induces changes in family dynamics (Koch and Jones 2018). While this study did not examine influences on the caregiving role of family members of children with cancer during hospitalization from a Nigerian perspective, the influence of ethnicity in the caregiving experience has been reported (Cook et al. 2018; Penrod et al. 2012; Pharr et al. 2014). The finding from this study that Hausa/Fulani caregivers have significantly better QoL than Yoruba and Igbo caregivers has exposed the possibility that cultural and social factors may affect the informal caregiving of pediatric patients with cancer in a diverse cultural and ethnic society like Nigeria. Although the reason for this finding is unclear, cultural and religious/spiritual factors may have some bearing. For example, it is known that the acceptance of the meaning of the diagnosis and even the possibility of death is more pronounced in Islamic religion (Khan and Saad 2022). This understanding may have diminished the negative emotions from the diagnosis and caring, thus optimizing their QoL. Second, women make up the majority of main caregivers in this study, and there is a difference in the number of working women in the southern and northern regions of Nigeria, with a greater number of southerners working outside the home (Gayawan and Adebayo 2015). If caring for their children took away their ability to work, it might have lowered their QoL, but for the Northern women who work mostly within the home, caregiving may have given them an opportunity for social networking that raises their QoL. However, assertion warrants further studies and buttresses the fact that QoL may differ between cultures and between ethnicities (Penrod et al. 2012; Pharr et al. 2014), thus revealing the importance of creating appropriate support services that reflect the socio-cultural needs of family caregivers of pediatric patients with cancer living in resource-constrained environments.

While addressing a gap in the research literature, there is a need for further rigorous evaluation to further determine how to adapt and optimize the intervention for maximum benefit to caregivers. This use of the theoretical framework of Andershed and Ternestedt (2001) provided the basis for guiding the development of content for the psychoeducation program. Future qualitative research may help to determine the scope for developing the existing content of the program, which in turn may help to inform the adaptation of the theoretical framework of Andershed and Ternestedt when applied in the context of a low-resource setting. Furthermore, we found a positive impact on the reported financial burden of participants for those who were employed. While specific content did not focus on financial burden, multiple opportunities arose for their discussion (e.g., more likely to be aware of sources of costs involved in ongoing and future care, opportunities for participants to share resources and contacts, and breakout sessions for discussions with social workers, nurses, or counselors). Findings such as these highlight the need for future qualitative research to explore the underpinning mechanisms responsible for changes in outcomes observed in the study. While evidence underpinning the benefits of PEIs is increasing (Gabriel et al. 2020), their place and relevance in routine clinical care within resource-constrained environments remain to be established. To ensure the successful uptake of these interventions in clinical practice, the synergy between family caregivers, clinicians (pediatric palliative care physician, pediatric oncologist, nurse, social worker), hospital management and a hospital-wide policy on respite care in cancer care is needed. At present in the study country, there is minimal recognition of caregivers in the national cancer control policy. A strong advocacy strategy targeting policymakers is needed urgently to ensure that the importance of the role of family caregivers in the cancer care continuum is highlighted, thus strengthening the need for the inclusion of interventions targeting caregiver needs in the cancer control policy.

Limitations

This study used questionnaires such as the PCS-PC scale that were not specifically designed for use with pediatric patients and had not been validated in the study environment, which could introduce bias. Additionally, the study used an uncontrolled before-and-after design and there was no comparison or control group, which could lead to selection bias. However, the study had a short time frame between the before and after the intervention, reducing the potential impact of confounding factors. The study design also made it difficult to determine the magnitude of the outcomes compared to a control group, and future research could be improved by using a control arm. Also, our enrolment approach did not guarantee that caregivers who participated may have been the most likely to benefit from the intervention. As observed, majority of children in this study had ALL and the care needs for these patients as well as the needs of their caregivers would probably differ from the needs of other children who had other forms of cancer as well as their caregivers too. The implication for this is the need for tailored approaches in pediatric oncology. Understanding these differences can enhance care strategies for affected children and their families. This study was the initial development and testing of the feasibility of the intervention. We hope that this work can evolve in future studies to consider the utility of multiple caregivers for hospitalized children with cancer. This could include, for example, screening of needs across caregivers, with efforts to identify specific individuals who could benefit from participation and then ensure tracking and involvement of these individuals.

Conclusion

This is the first study to explore the feasibility of developing and implementing a PEI for delivery in the hospital setting for informal caregivers of children s suffering from cancer in an African context. The PEI was able to improve cancer and palliative care knowledge and skills as well as increase the confidence of informal caregivers with regards to care of pediatric patients with cancer leading to significant reductions in unmet needs and high burden level of informal caregivers. It empowered informal caregivers with the requisite knowledge to continue care of patients beyond the hospitalization phase. While the toolkit did appear to support reductions in CB, future phases of this research will importantly need to explore the impact of the toolkit on psychological vulnerability and psychological health. Development and refinement of the psychosocial intervention for caregiver–child dyads in resource-limited settings is paramount to the well-being of the informal caregiver and will help accelerate the success of the WHO Global Initiative on Childhood Cancer that seeks to reduce suffering for all children with cancer by the year 2030 (WHO 2020). The intervention resonates with the 3-year campaign of the International Childhood Cancer Day (ICCD) of which its 2023 campaign theme, ***#throughtheirhands***, aims to pay tribute to caregivers and families as well as reveal the impact that they have on pediatric patients with cancer· In addition, the ICCD “Tree of Life” reflects 10 elements for better survival of children with cancer, 2 of which are family support and palliative and supportive care (ICCD 2022). We posit that this research has contributed to developing the evidence base for the development of effective informal pediatric family caregiver support systems in SSA. However, there is a need to consider how and under which circumstances peripheral elements may be supported to promote good QoL for the informal caregiver during the hospitalization period. It is suggested that future research should examine the impact of external stressors on the QoL of informal caregivers in SSA during the hospitalization of a child with cancer. The findings of this research may guide important outcomes for caregivers and improve holistic care for them. It is hoped that this research will lead to more research on PEIs for resource-poor environments, and will encourage hospital administrators and policymakers to create and support psychoeducation courses and in-hospital respite care programs for informal pediatric cancer caregivers as a routine practice during hospitalization to make the caregiving experience more manageable.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1478951524000178.

Acknowledgments. The authors thank all doctors, nurses, and other clinicians in the pediatric oncology units of participating hospitals for their cooperation and support during this research.

Funding. This work was supported by a grant from the Rally Foundation for Childhood Cancer Research, Atlanta, Georgia, USA.

Competing interests. The authors have no conflict of interest to declare.

Ethical approval. Ethical approval was obtained from all sites (UNTH: NHREC/05/01/2008B- FWA00002458-IRB00002323; LUTH: ADM/DCST/HREC/APP/2584; JUTH:JUTH/DCS/ADM/127/XXVIII/1352; AKTH: AKTH/MAC/SUB/12A/P-3/VI/1802). International ethical norms and standards were strictly adhered to. Written informed consent was obtained from all participants. Participation was voluntary. The study was reported according to the STROBE Checklist (Appendix A).

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