Niger J Paediatr 2022; 49 (1): 8 – 13

ORIGINAL

Adedayo Joseph
Adeseye Akinsete
Bolanle Adegboyega
Opeyemi Awofeso
Mutiu Jimoh
Muhammad Habeebu

Childhood cancer in Nigeria: The effect of a handbook in the experiences of caregivers

DOI:http://dx.doi.org/10.4314/njp.v49i1.2

Accepted: 15th November 2021

Adedayo Joseph (✉)
Adeseye Akinsete
Bolanle Adegboyega
Opeyemi Awofeso
Mutiu Jimoh
Muhammad Habeebu
Lagos University Teaching
Hospital, Lagos, Nigeria.
Email: djoresearch@gmail.com

Abstract: *Background:* Parents of children diagnosed with cancer are handed a frightening diagnosis, with attendant emotional, social, and financial challenges. They often have many questions that remain unanswered by busy doctors and nurses, who are themselves overwhelmed by the challenges of caring for cancer patients in resource-constrained circumstances. The objective of this study is to evaluate the impact of a childhood cancer handbook on the experience of caregivers of children diagnosed with paediatric cancer in Nigeria.

Methodology: A series of focus group discussions involving caregivers of children with histologically diagnosed cancer were held. A childhood cancer handbook was given to each participant to read. Data was collected four weeks later and analysed using qualitative content analysis.

Results: In general, 91.7% of focus group participants reported that they found the handbook useful and having it at diagnosis would have significantly increased their level of information and made dealing with the diagnosis more tolerable. However, many of the participants reported that while the book completely catered to their informational and emotional needs, it did not adequately address certain practical needs such as paying for cancer treatment.

Conclusion: Many Nigerian families go through the entire paediatric cancer journey, feeling like they are stumbling in the dark. No dedicated information resource on paediatric cancer exists in Nigeria. The provision of a detailed handbook at diagnosis may reduce the psychological and emotional toll of a cancer diagnosis on parents and family of a child diagnosed with cancer.

Keywords: Paediatric Cancer, Caregivers, Handbook, Cancer Support, Information, Patient Education

Introduction

Chronic, non-communicable diseases like cancers can be catastrophicto the family of the affected individual.[1]While financial concerns are often paramount, it is more pronounced in a resource-constrained setting where treatment costs are almost exclusively paid out of pocket with associated profound psychological and mental toll on patients, siblings, parents and the family at large.[2] Parents and families of children with cancer find themselves plunged into a period of unprecedented crises upon the diagnosis of cancer. They are handed a frightening diagnosis, with the attendant emotional, social, and financial challenges that accompany a cancer diagnosis[3,4]. They often have little information and several unanswered questions.[5]

For many parents and caregivers of children living with cancer in developing countries like Nigeria, diagnosis is the first time they even become aware of the possibility of cancer in a child.[6] They have many questions including; 'why does my child have cancer',' is cancer a consequence of an action or inaction on my part',' what about my other children, are they at risk',' can a child survive cancer', and 'what does the future hold if he/she does survive cancer?' Due to the limited resources of paediatric cancer management in developing countries like Nigeria, efforts are often invested in the amelioration of the perceived and documented barriers to care such as early detection, community awareness, and even financial constraints.[7,8] Many of the questions that caregivers of paediatric cancer patients have, remain unanswered by busy doctors and nurses who are themselves overwhelmed by the challenges of caring for cancer patients in a resource-constrained environment like Nigeria.[9] While addressing inarguably important factors such as delayed detection and presentation, other aspects of paediatric cancer care like information, education, and psychological support for both the children and their caregivers often remain overlooked. This lack of information may contribute to poor outcomes in ways not wholly explored or understood.[10–12]

To help caregivers navigate the tortuous landscape of paediatric cancer diagnosis and care, a simple and inexpensive resource was developed—a handbook with easy-to-understand information for parents and caregivers. The book was designed for caregivers and children with cancer in Nigeria to answer some of the most common questions they may have following the diagnosis of cancer.

Study aim

The objective of this study was to evaluate the impact and value of a patient education resource, 'the childhood cancer handbook' on the experience of caregivers of children diagnosed with cancer in Nigeria.

Materials and methods

This was a qualitative study design with the use of semi-structured interviews in focus group discussions. Recruitment of study participants was by a mix of purposive and snowballing sampling methodology. Study participants were parents or caregivers of children with a confirmed cancer diagnosis and were recruited from a paediatric cancer support group.

Each participant was given a free copy of the cancer handbook, and four weeks to read the book; with the expectation of participation in a focus group at the end of the four weeks. Caregivers who could not read in English were excluded from the study.

The cancer handbook is a tool authored by an oncologist with a special interest in paediatric oncology; and distributed at no charge to paediatric cancer patients, caregivers and healthcare providers by a non-profit organisation working to improve paediatric cancer survival in Nigeria. The handbook is a free resource created to serve as a source of information for older children and adolescents, caregivers, and healthcare providers of children with cancer. The handbook is arranged in chapters and set in a question-and-answer format. It attempts to explain in simple terms what cancer is and how it develops, common cancer-related terms or jargon (e.g. benign or malignant), and address myths and misconceptions. It also provides information about common paediatric cancers, the signs and symptoms, and the common treatment modalities. The final chapter focuses on the social and psychological aspects of the paediatric cancer diagnosis and how to talk to a child living with cancer. Other issues such as relapse, fertility, and late effects of cancer treatment are also addressed.

Participants were reviewed after four weeks and data was collected using a semi-structured questionnaire and discussion guide. Participants were divided into six focus groups of 10 each. Each session lasted about 90 minutes and was documented using a voice recorder and handwritten notes.

The interviewer guide employed the use of open questions framed in everyday language free of technical terms and which avoided the use of leading questions. Data were then transcribed, coded, categorised and analysed by similar themes in the answers using inductive content analysis as defined by Patton.[13]Reports were depicted using verbatim quotes to illustrate the findings of the study. Identities of all participants in the study were protected by using a code.

Ethical approval was obtained from the Health, Research and Ethics committee of the Lagos University Teaching Hospital. Written informed consent was obtained from all the caregivers included in the study before the commencement of the study.

Results

A total of 79 participants representing children with histologically diagnosed cancers were approached for the study. The patient and caregiver's sociodemographic and economic characteristics, as well as the patient's clinical history and cancer diagnosis, were documented. (*Table 1)*Eleven participants declined to participate while the 68 who consented to the study were given the handbook. Seven participants either dropped out of the survey or did not finish reading the book in the stipulated time of four weeks, and one participant moved out of state.

The participants' sociodemographic characteristics are provided below; median age of their children was six years (range: 2-15years) and with a slight male preponderance. The most common diagnosis was Leukaemia representing almost half (46.7%) of all patients recruited. Over three-quarters, (87%) of patients were at advanced stages of the disease at the time of diagnosis. The median age of the caregivers was 41.5 years, with ages ranging from 30 to 69 years. The most common participating caregiver group was mothers (60.0%). (Table 1)

Table 1: Participants characteristics

	Patients (n=60)	Caregivers (n=60)
Sex, n (%)		
Females	24(40.0)	46(76.7)
Males	36(60.0)	14(23.3)
Age in years, median (range)	6(2-15)	41.5 (30-69)
Time since diagnosis in months, median (range)	9.5(6-41)	
Diagnosis, n (%)		
Leukaemia	28(46.7)	
Lymphoma	8(13.3)	
CNS tumours	4(6.7)	
Retinoblastoma	4(6.7)	
Wilms tumour	8(13.3)	
Osteosarcoma	2(3.3)	
Rhabdomyosarcoma	6(10.0)	
Stage at diagnosis		
Early	8(13.3)	
Advanced	52(86.7)	
Primary caregiver		
Mother		36(60.0)
Father		14(23.3)
Grandmother		6(10.0)
Aunt		4(6.7)

The analysis from the group discussions produced four overarching themes which addressed the research question on the usefulness and drawbacks of the handbook in the paediatric cancer journey. The four themes include the informational & educational usefulness, emotional & psychological usefulness, the financial and social usefulness of the cancer handbook and reported limitations noted with the use of the tool.

Informational and educational value of the cancer handbook

The session began with most caregivers stating the major challenges faced following the diagnosis of cancer in the children, including difficulty communicating with the healthcare provider about the concerns they have regarding the diagnosis and care of the child with cancer. When the discussion about the lack of information following the cancer diagnosis was broached in the groups, all participants uniformly stated that they had questions and required guidance on what to do after the diagnosis was made. Only 13.3% of caregivers reported that most or all of their questions were answered by the attending healthcare professionals following the diagnosis of cancer in their children.

'We don't always get to see our consultant. The doctors are usually always in hurry (sic);they just want to see the test results before they will even talk to you. I feel as if I am disturbing the doctor if I ask plenty of questions. And even other patients waiting will not be happy if you take too much time.'

'I usually just use 'goggle' (sic) to check anything I don't know. But when I come to the clinic to confirm, they will sometimes laugh or even behave as if I am wrong for checking goggle (sic). They will just be saying: 'don't worry, don't worry' I wrote down some questions from the book and asked my doctor, he was more receptive to answering me than when I checked google, we really had a useful and informative conversation from there.'

'I wish we had this book when my son was just diagnosed nine months ago. I had so many questions but I was too afraid to ask the doctor because he was always in a hurry.'

'All I wanted to know when we found out that my child had cancer was 'was he going to die?' but every time I asked my doctor, he just said everything was going to be fine but I could felt (sic) that he was lying and some of the other children we met in the ward died. With the book, it helped me know that many children all over the world are going through this too and that many of them survive so my child can survive too.'
'It would have been better if they gave me this book since, it answered many of my questions'

Emotional and Psychological value of the cancer handbook

A common question following diagnosis especially for many of the female participants was surrounding causality and guilt. Many wondered if this had happened to their child due to something they may have eaten or drunk while pregnant; others wondered if they had failed to take some important vitamin or supplement. Many reported that they had been told or had heard it insinuated by different sources that they had somehow contributed to their child's predicament. Many mothers reported feeling a deep sense of guilt, shame, and helplessness, both at the diagnosis of the affected child, and their powerlessness to understand how to 'solve' it. For many, their only resource was their faith and prayer. Almost all (81.7%) reported it was a great relief to read that nothing they had eaten, done, or failed to do, was likely to be responsible for their child developing cancer.

'I was worried that my child had cancer because of something I did, maybe before I even got married or because I had done an abortion before I got married. The book helped me realise that it was not my fault. Things just happen'

'My husband's grandmother came to our house, shouting and calling me a witch, advising my husband to send me and my child out of the house. I just thank God for my husband. I gave my husband the book to read when I was done with it, it has not solved all of our problems, but it made a difference.'

'I learnt from the book how to talk to my child and to carry my other children along too. My son even read the book after me and he told me that he never understood everything that was going on, he just thought it was his fault that I was sad all the time. I explained to him that it

was not his fault.'
'It was not my fault. It was nothing I did wrong. In fact, it is not anybody's fault. It is just meant to be.'

I have been thinking a lot about money, about if she will survive, many things. When I read this book, I realised I have to talk to her about it. I used the chapter the way it was, and she was very happy when we talked. She cried and we hugged.'

Financial and Social value of the cancer handbook

There were also concerns about education continuity and stigmatisation/ostracization. Caregivers wanted to know if it would be safe for the child to return to school and be active. For those whose child/ward was in school at the time of the study, participants had questions about the impact of treatment on academic ability. Many reported that their child had been doing better academically in the past. While all participants had concerns about the financial burdens of the cancer diagnosis, this concern was predominant amongst male caregivers.

'*My son was always first in his class before all these cancer problems started, now he can't even go to school to be with his mates, I am sad that he is missing out. I don't know when he will eventually be able to go back to schools and if he will still be first in his class like before but the book said to take it one day at a time so that is what we are doing. I have also learnt to start considering other options for teaching him so he will not be left behind.'*

'It would have been nice to have this book in the beginning to give me an idea of how expensive this cancer thing is (sic). I remember asking how much the whole treatment would cost. The young doctor I asked said he does not know, but I should just budget about 10 million naira. I am a cashier in the bank where am I supposed to get that type of money from? I just looked at him because I wonder how he would feel if someone should ask him to bring out 10 million naira now'

'My son and I have been coping with this cancer for over five years now. I have three other boys. He is my firstborn. He is a good boy and I am ready to do anything to make sure he will live. I have sold everything I can sell, if not for donations, by now I wonder how I will be paying for treatment but at least I know I am not alone.'

In general, 91.7% of all participants reported that they found the handbook very useful. All of the patients and female caregivers found the book useful.

Perceived Drawbacks

Ten out of the fourteen male participants reported that they did not find the handbook useful. The common denominator being the failure of the tool to cater to their financial needs.

'*The book does not tell me how to get the money for treatment for my child; all the things written in the book was not really my problem.'*

'Maybe for people who have plenty money they can be worrying about feelings and all those things. I am jobless, I can't buy chemo, there is rent, I have other children's school fees. This book cannot solve my problems at all'

Thirty percent of participants reported that the book was too wordy, did not have enough images and pictures, or was difficult to read to the end.

'Some of the chapters were like reading for exam.'
'…maybe if they put more pictures it will be easier to understand.'
'…with everything going on, it was hard to find time to read it.'
About 13.3% of participants reported that even with the book, they were unsure what the future holds for their child or that they no longer needed the book.

'My child has finished treatment and cancer has gone; this book would have been useful to me when we first found the cancer'

Finally, the participants noted that the handbook could prove more useful if contact details of financial aid organisations and more information about was to do once treatment was completed were included. Some participants also noted that translating to local languages or making it even simpler for younger children would increase its value.

Discussion

"Information is power."

Information is critical to the psychological and emotional state of caregivers of children diagnosed with cancer. Better patient education may also improve prognosis, possibly through a reduction in treatment drop-out rates and increased compliance and commitment to the treatment plan.[14] Cornelio et al., outlining the experiences of mothers of children with Leukaemia, found that the mothers reported the cancer diagnosis as pivotal moments in their lives requiring a great deal of support and adjustment.[15]

Almost all the caregivers (91.7%) in the focus group discussion reported that that they found the handbook useful and having it at diagnosis would have significantly increased their understanding of about their child's diagnosis, the treatments being administered, side effects to expect and what to do. This, is similar to findings from a study by Wakefield et al. in 2011 where parents of children with cancer reported that they prefer information booklets for use in answering their questions on childhood cancer[16]

Several studies have reviewed the concerns of paediatric cancer patients and their parents or caregivers, noting concerns ranging from the understanding of cancer and its treatments, to its impact on life during and after treatment[11,17,18]. The focus group discussions outlined some of these concerns, including questions regarding diagnosis, causality, and survivorship. In this study, we found that only 13.3% of caregivers indicated that they had most of their questions answered by the healthcare professionals following the diagnosis of cancer in their children; indicating that the vast majority of caregivers (86.7%) needed more information than they were provided with. This is similar to findings from a review of 115 caregivers of children with cancer by Njuguna et al in Kenya where 88% of respondents stated that they needed more information about the diagnosis and treatment than they were provided with during the course of the cancer.

Almost half (48%) reported being confused by the doctor's vocabulary, 52% and 28% respectively could not attend more doctors' visits due to travel and hospital costs respectively.[19]

This study revealed the significant gap in supportive resource provision for parents and caregivers of paediatric cancer patients in Nigeria. Most study participants reported that an inexpensive resource containing detailed information regarding their child's diagnosis, treatment, and prognosis would be of value to them.

The most significant deficiency was the fact that the book did not provide a concrete solution to the financial strain experienced by parents going through cancer with a child. Information about how to access available financial aid and contact information for non-profit organisations which support children diagnosed with cancer will be included in subsequent editions of the book.

Conclusion

A cancer diagnosis in a child would plunge any family into turmoil and patients, parents and caregivers have many questions. No dedicated and widely available patient education and information source on paediatric cancer exists in Nigeria. Many parent and caregiver questions remain unanswered, and many concerns remain unresolved. The provision of a free handbook to every child and their family at diagnosis can reduce the emotional and psychological strain; and help families cope with the experience of paediatric cancer.

References

1. Mcloone JK, Ellis SJ, Cohn RJ. It's More than Dollars and Cents: The Impact of Childhood Cancer on Parents' Occupational and Financial Health. *Article in J Psychosocial Oncology. 2014 Sep 3;32(5):602–21.*
2. MW MS-, Andrésrtin undefined, Psycho-Oncology editors. P, 2012 undefined. Psychiatric impact of childhood cancer. Wiley Online Library.
3. Roser K, Erdmann F, Michel G, … JW-P, 2019 undefined. This is a repository copy of The impact of childhood cancer on parents' socio-economic situation-A systematic review. Wiley Online Library. *2019 Jun 1;28(6):1207–26.*
4. Moore JB, Kaffenberger C, Goldberg P, Kyeung Mi Oh, Hudspeth R. School reentry for children with cancer: Perceptions of nurses, school personnel, and parents. *J Pediatric Oncology Nursing. 2009 Mar;26(2):86–99.*
5. Lindahl Norberg A, Boman KK. Acta Oncologica Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress symptoms, depression and anxiety. *Taylor & Francis. 2009;47(2):267–74.*
6. Chukwu BF, Ezenwosu O, Nnaemeka Ikefuna A, Emodi I. Article in Pediatric Hematology and Oncology. *Taylor & Francis. 2014 Feb 17;32 (2):164–71.*
7. Howard S, Zaidi A, Cao X, Weil O, Bey P, … CP-TL, et al. The My Child Matters programme: effect of public–private partnerships on paediatric cancer care in low-income and middle-income countries. Elsevier.
8. Kruger M, Hendricks M, Davidson A, Stefan CD, van Eyssen AL, Uys R, et al. Childhood cancer in Africa. *Pediatric Blood and Cancer. 2014 Apr;61(4):587–92.*
9. Chirdan L, … FB-T-AJ of, 2009 undefined. Childhood cancers: Challenges and strategies for management in developing countries. afrjpaedsurg.org.
10. Ribeiro R, Steliarova-Foucher E, oncology IM-T lancet, 2008 undefined. Baseline status of paediatric oncology care in ten low-income or mid-income countries receiving My Child Matters support: a descriptive study. Elsevier.
11. Patterson JM, Gurney JG. Parental Involvement and Family-Centered Care in the Diagnostic and Treatment Phases of Childhood Cancer: Results from a Qualitative Study. *Article in J Pediatric Oncology Nursing. 2003 Nov;20(6):301–13.*
12. Grassi L. Epidemiology and Psychiatric Sciences Psychiatric and psychosocial implications in cancer care: the agenda of psycho-oncology. cambridge.org.

13. Qualitative Research & Evaluation Methods - Michael Quinn Patton - Google Books [Internet]. [cited 2021 Jan 17]. Available from: https://books.google.com.ng/books?hl=en&lr=&id=FjBw2oi8El4C&oi=fnd&pg=PP21&ots=bxmZjFOHxL&sig=J2J0inG60qkODmc0kGSOoEEljiA&redir_esc=y#v=onepage&q&f=false
14. Wiener L, Viola A, Kearney J, Mullins LL, Sherman-Bien S, Zadeh S, et al. Impact of Caregiving for a Child With Cancer on Parental Health Behaviors, Relationship Quality, and Spiritual Faith: Do Lone Parents Fare Worse? *J Pediatric Oncology Nursing. 2016 Sep 1;33 (5):378–86.*
15. Cornelio S, Nayak B, care AG-I journal of palliative, 2016 undefined. Experiences of mothers on parenting children with leukemia. ncbi.nlm.nih.gov.
16. Wakefield CE, Butow P, Fleming CAK, Daniel G, Cohn RJ. Family information needs at childhood cancer treatment completion. *Pediatric Blood & Cancer. 2012;58(4):621–6.*
17. Jervaeus A, Nilsson J, Eriksson L, … CL-EJ of, 2016 undefined. Exploring childhood cancer survivors’ views about sex and sexual experiences-findings from online focus group discussions. Elsevier.
18. Nilsson J, Jervaeus A, … CL-H, 2014 undefined. ’Will I be able to have a baby?’Results from online focus group discussions with childhood cancer survivors in Sweden. academic.oup.com.
19. Njuguna F, Mostert S, Seijffert A, Musimbi J, Langat S, van der Burgt RHM, et al. Parental experiences of childhood cancer treatment in Kenya. *Supportive Care in Cancer. 2015 May 1;23 (5):1251–9.*