



Psychosocial Issues Experienced by Parents of Children with Cancer in Southern Nigeria

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Author's contribution

The sole author designed, analysed, interpreted and prepared the manuscript.

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ABSTRACT

Background: Childhood cancers have been on the rise globally. Parents of affected children have to cope with pressures and stresses of treatment often associated with a significantly increased risk of psychosocial issues.

Objectives: To explore the experiences and psychosocial issues of parents whose children were diagnosed and are undergoing treatment for cancer.

Methods: This qualitative study was conducted between June and November 2018. Data were gathered through semi-structured interviews held with 27 parents whose children were being treated for various cancers at the Paediatric Oncology Unit of the University of Port Harcourt Teaching Hospital, Nigeria.

Results: Prior to diagnosis, knowledge of respondent about childhood cancers was deficient. Shock, disbelief and anxiety were often experienced when diagnosis was made known, while fear of the unknown and fear of death were significant concerns. Challenges at the workplace, especially lack of concentration and frequent absences were causes of added distress to mothers, while having a support group was a perceived need to help parents cope better. Positive behavioural changes in families were identified in the course of the child treatment.

Conclusion: Parents caring for children with cancer face a wide range of distresses. There is need to empower healthcare providers as well as community members on ways to support these parents and help them cope with their child's illness and treatment.

Keywords: Psychosocial issues; parents; childhood cancers; Southern Nigeria.

1. INTRODUCTION

The World Health Organization (WHO) recommends that children with life-limiting illnesses such as cancers be offered palliative care which is the active total care of the child's body, mind and spirit and giving support to the family, from diagnosis, regardless of whether or not the child receives the curative treatment [1]. One hundred and seventy-five thousand new cases of childhood cancers and 96,000 deaths are recorded annually among children aged 0 to 14 years, with 90% of these deaths occurring in developing countries [2,3]. With the global rise of this scourge, the need for paediatric palliative care services is increasingly being recognised. Furthermore, it has been reported that 98% of children in need of palliative care live in low- and middle- income countries (LMIC), with almost half of them living in Africa [3].

The psychosocial aspect of care refers to the dynamic relationship between the social and psychological experiences, where the effects of one continually influence the other [4]. In childhood cancers, it addresses a very wide range of issues, and has to do with the various facets of care that are linked to the specific treatment of illness. They include among others, housing especially when treatment centre is in a far away location, transport to the treatment centre, finances, invasive treatment and its effects, uncertainty of prognosis and role shifts within the family [4,5]. These often result in various forms of distress family members suffer with regards to the child's illness and its treatment.

Parents caring for children with cancer have reported feelings of anxiety, fear, depression and distress related not only to the care of the affected child, but also to the adjustment of the child's siblings who have also reported feeling anxious, stressed, overwhelmed, neglected and guilty [5-7]. On the other hand, some factors and interventions have been found to have the potential to minimise the negative impacts of cancer on the child and his/her family, including having high levels of support from the family, classmates, school and the hospital [8,9].

In several studies in high income countries, where social services and health insurance are functional, the psychosocial impacts of childhood malignancy on the family has been explored and

found to be profound [7,8,10]. Whereas in most sub-Saharan African countries, statutory social security programmes to protect and care for the underprivileged, are often not functioning fully and are rarely easily accessible to vulnerable children [4]. Furthermore, with the scarcity of palliative care services, parents are often denied the support they could benefit to help them cope with the exigencies of their child's therapy.

Identifying the psychosocial issues childhood malignancies imposed on the parents in our environment, especially the mother who is usually the primary caregiver, becomes important in order to understand their experiences and work out efficient psychosocial interventions.

Thus this study aimed to explore the experiences and psychosocial issues of parents whose children were diagnosed and are undergoing treatment for cancer.

2. SUBJECTS AND METHODS

The study was conducted at the University of Port Harcourt Teaching Hospital (UPTH), a tertiary care facility and reference cancer center located in the Niger Delta region of Nigeria. It serves patients from within Rivers State, which has an under-15 population of 2,437,138; and neighbouring states [11]. With the National Health Insurance covering about 5% of the population, financing for childhood cancers in Nigeria is mainly through out of pocket payment [12].

Respondents in this qualitative cross sectional survey included parents whose children were undergoing treatment for various childhood malignancies for at least 3 months, at the Paediatric Oncology unit of the UPTH, between June and November 2018 as well as some who had lost their children to cancer. Data were collected when parents brought their children for follow-up visits. Those who had lost their children to cancer (2) were visited at home and accepted to be included in the survey. Participation was voluntary.

Twenty-four semi-structured interviews were conducted in English or Pidgin English languages. In 3 instances, both parents participated, giving a total of 27 participants. Biodata and socio-economic status of respondents were obtained, while key topics of

interviews included their knowledge and perception of childhood cancers, experience at disclosure of diagnosis, psycho-social issues experienced in the course of caring of their child, and perceived needs to cope better with their child's illness. The interviews, which lasted 35-45 minutes each, were recorded with permission and all recordings were transcribed by the researcher.

Patients were grouped into social classes according to the system of Oyedeji, using educational levels and occupation of parents [13]. Those in socioeconomic classes I and II were grouped as high; those in III as middle and those in IV and V as low income groups.

Approval for the study was obtained from Medical Ethics Committee of the Hospital and informed consent letter was obtained from the parents who participated in the study.

Based on the approach of Braun and Clarke, the sentences and paragraphs were considered as meaning units, and were coded and named based on their hidden concepts. The codes were compared based on their similarity and dissimilarities and the themes emerged [14]. Simple frequency analysis was carried out with the Statistical Package for Social Sciences (SPSS) version 25 software.

3. RESULTS

Twenty-four interviews were conducted. Respondents were 19 mothers, 2 fathers, while in 3 instances both parents participated in the interviews (Table 1).

Their children were aged 1 to 15 years, with a median age of 5 years at the time of the study. Among them, 13 belonged to the 1-5 years age bracket, 7 were 6-10 years and 4 were 11-15 years old (Fig. 1).

Table 2 shows the themes and sub-themes explored during the interviews.

Knowledge and perception about childhood cancer revealed that prior to diagnosis, many parents were not aware that cancers can also affect children, and the large majority had no idea of what could cause cancer in children.

The father of a 3 year old girl with neuroblastoma: "... How did I land with this?... What did I do wrong?...". However, few

mentioned inappropriate diet and family inheritance. Doctors were said to be their major source of information about childhood cancer, and the media also play a role for many while few got their information from other mothers who also cared for children with cancer. Surprisingly only one mother mentioned getting information from the nurses. This was supported by the experience of another mother: "... Nurses are nice. Apart from given medication and taking vital signs, they do not have much to do with us...".

Few parents were worried about infertility later in life as possible complication of cancer treatment, while 2 mothers whose children were undergoing treatment for recurrent disease pointed out that recurrence is a serious complication. Most respondents, however, were not aware of possible complications of treatment.

Many parents mentioned shock, fear, anxiety and disbelief when they first heard about the possible diagnosis, even when it was not yet confirmed. A mother: "... We had been on admission for few days, when I was told that it was confirmed my 2 year old son has acute leukaemia, I did not believe that could be possible but later on that day, I was devastated and became numb..., nothing meant anything for me anymore and that went on for several days. Is it normal?..."

On the other hand, the mother of a 2 year old girl mentioned guilt which was worsened by the statements radiographers made when she went to have an ultra sound scan for her daughter who was found to have an abdominal mass due to hepatoblastoma. "...They asked me several times how it was possible that I did not detect such big mass in my child's tummy. They were using harsh words, and it looked like I was not a caring mother. I was so depressed after that scan.... "

Two mothers expressed helplessness. One of them: "...Am a widow taking care of my 4 children all alone. It has been difficult... when I was told my son has leukaemia, aah... I kept asking myself, where will I start from?..."

In recalling the fears and concerns they had about the illness at diagnosis, fear of what will come next was mentioned by the majority of respondents, while fewer revealed that fear of death and cost of treatment were their major concerns. Only two mothers were worried about the pain their child will have to go through.

Table 1. Demographic details of respondents

Characteristics		N
Parents	Mothers	19
	Couples	3
	Fathers	2
Age	20-29 years	2
	30-39 years	14
	40-49 years	11
	≥ 50 years	0
Education	Tertiary	17
	Secondary	9
	Primary	0
	No formal	1
Occupation	Professional	8
	Non-professional	12
	Unemployed	7
Marital status	Married	23
	Single mothers	2
	Widowed	2
Socio-economic class	High	8
	Middle	10
	Low	6

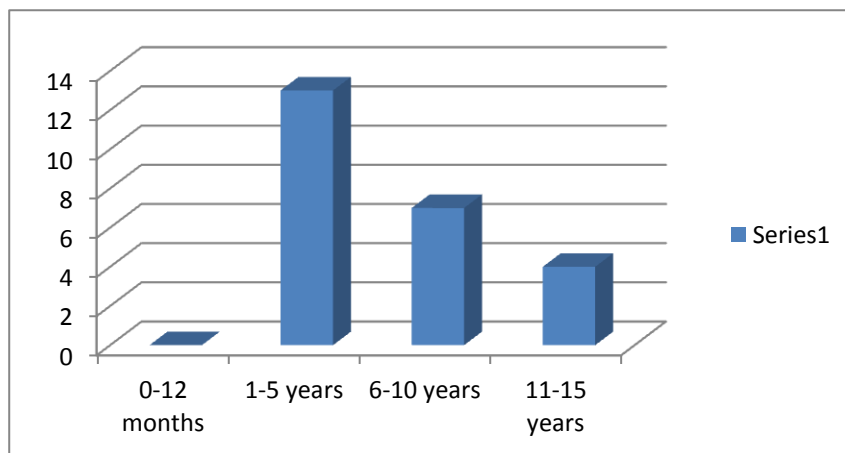


Fig. 1. Age distribution of children

Table 2. Themes and subthemes explored during the interviews

Themes	Sub-themes
Knowledge and perception about childhood cancer	Awareness that cancer can affect children
	Possible causes of childhood cancers
	Source of information on childhood cancers
	Complications of cancer treatment in children
Disclosure of diagnosis	Reaction at disclosure of diagnosis
	Communication with healthcare providers
	Fears and concerns about newly diagnosed illness
Psycho-social issues experienced in the course of caring of their child,	Psychological effects
	Causes of added distress in the course of the child's therapy
	Positive aspects of experience with children's cancer
	Perceived needs to help parents cope better with child's illness

Exploring causes of added distress for parents in the course of the child's therapy revealed that many working mothers had challenges at their workplaces, which included among others lack of concentration and frequent absences because of child's numerous hospitalisations. This led to loss of job for 2 mothers who were working in private firms, one of them was a single mother. A mother: "... The anxiety is much, it is difficult to concentrate at work. You keep thinking about how to meet up with the next course of chemotherapy and investigations, how is your child doing. It is not easy to care for a child who can develop all sorts of symptoms anytime...". Three self employed mothers, all traders, had their businesses shut down as all available funds in the family were channelled to cancer treatment.

A mother: "...it has not been easy, as if to crown it all, our only car was stolen when we went for a crusade by a great evangelist who came into town. We went seeking for divine healing for our daughter. And now with the frequent hospital visits, transportation is a big problem... "

In the midst of it all, parents were able to identify some new occurrences in the course of the cancer treatment, which were seen as positive aspects of their experiences with children's cancers. Family members, especially husbands, were encouraging and became more caring, which became a source of strength for many mothers.

"... My siblings call more often just to check on us, which was not happening before my son's diagnosis and treatment. They keep encouraging me... ";

"... my 13 year old daughter is showing so much maturity now. When am in hospital with the sick one, she cares for her younger ones at home, ensuring they are not missing mummy too much...";

"... I now know many doctors and have made friends with some of them...";

Perceived needs to help parents cope better included financial support, more information about the child's illness, to have more contact with doctors, have a support group to share problems and concerns. The needed information about the child's illness centred around nutrition

in cancer, prognostic/survival, information on the disease and treatment and how to prevent/overcome relapse. A mother: "...I am just lost, not knowing what is recommended for my child. To get him eat is a big task... What type of food should we give him? Some mothers have advised me to be giving him <Hospital too far> to drink and use it as vegetable in his meals. Is it ok?..."

4. DISCUSSION

This study reveals a lack of adequate knowledge of matters surrounding childhood cancers. Such has also been reported among the general community in Africa [15-17]. Besides, the concept of children's cancer is still unfamiliar to lay people, while the fact that some of them present with symptoms similar to those of common childhood illnesses, makes recognition difficult. However, this lack of adequate knowledge is of concern, considering that the respondents' children had been on treatment for at least 3 months preceding the survey. It brings forth pertinent issues about communication and counselling on the disease that families undergo prior and during treatment. Moreover, several authors agreed that relevant information is understood by parents if given consistently by the health care professionals [15,18,19]. This highlights the need to empower healthcare providers with skills to enable them offer optimal support, including information, to children with cancer and their parents.

For some affected parents, the diagnosis of childhood cancer is one of the most intense and painful experiences that a parent can have [15-17]. The shock, disbelief, fear, anxiety and helplessness reported by respondents in this study have all been previously documented [7,15,17]. This is understandable because of the life threatening nature of the illness, while the gross lack of information on the subject may further heighten these feelings. These emotional issues are real, unfortunately, they are often neglected. This has been corroborated by several authors who found that communication about the illness, between the medical team and parents of children with cancer, was limited to medical matters [18,20]. Besides, Manicom rightly pointed out that there is more to cancer care than medical management, as family members who are carers have also been identified as being at risk of manifesting physical exhaustion and/or emotional stress and burnout

[6]. In the same vein, Naidoo et al. in South Africa found that parents were overwhelmed by their experience of having a child with cancer, and expressed the need for psychological intervention, which may go a long way in addressing the fears and concerns parents may have about the newly diagnosed illness [17].

The importance of psychosocial interventions should not be overlooked. The unprecedented progress made in the cure rate for childhood cancer during the past four decades in high income countries has been attributed to steady improvement in treatment protocols, as well as multidisciplinary approach to patient care, adequate hospital infrastructure, and psychosocial and economic support for affected families [21]. Thus, there is great need for health care providers in developing countries to assist parents as they deal with the diagnosis and treatment of their children by appropriately introducing psychological treatment to the family, as well as patients, not only as addition to the physiological treatment they administer, but as part of the same regimen [5,10]. Nonetheless, it is also known that the way people react and adjust after a diagnosis varies and is dependent on many factors which could be disease-related, socio-ecological and child-related [22]. Assessing risk factors across these levels makes it possible to predict future psychosocial distress and to intervene accordingly. The Psychosocial Assessment Tool (PAT), which is a brief parent-reported screening tool that aimed at detecting families at risk for psychosocial difficulties in pediatric oncology, has been recommended for use shortly after the diagnosis of childhood cancer [23]. However, its usability in our setting is subject for a future study.

Cancer treatment has the potential to push families into or exacerbate poverty, especially in resource limited settings, where health care is accessed mainly from out of pocket payments. Nevertheless, most communities have some support systems, formal and informal. Among these are individual people (members of extended family, friends, neighbours and professionals), or community and social groups (such as churches, Community Based Organisations etc.), which may be able to help the child and family with their many needs, whether emotional, financial, childcare, transport or spiritual. This can make the family feel cared for, valued, and respected during a time of stress [4,5]. Besides, there is strong evidence that

family caregivers who receive social support cope better, feel less depressed and report less stress compare to families who are alone or isolated [24,25]. This highlight the importance of introducing parents of children with cancer to cancer support groups, which are avenues where families are helped, receive information and share challenges and concerns, learn coping strategies from those who had similar cancer experiences. Joining a support group has been shown to improve quality of life and survival [26].

It was encouraging to note that some parents identified positive changes in their families since their child was diagnosed with cancer, as they attested to strengthened family bonds, which lessened the stress they were going through.

5. CONCLUSION

Parents caring for children with cancer faced a wide range of distresses, including emotional and financial. There is therefore need for community awareness on matters related to childhood cancers and empowerment of both health providers and community members on ways to support parents of children with cancer and help them cope with their child's illness and treatment. Introducing psychological treatment for the family, as well as patients as part of the child's treatment regimen is recommended

CONSENT AND ETHICAL APPROVAL

Approval for the study was obtained from Medical Ethics Committee of the Hospital and informed consent letter was obtained from the parents who participated in the study.

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COMPETING INTERESTS

Author has declared that no competing interests exist.

REFERENCES

1. World Health Organization. Definition of Palliative Care; 2002. Available:<http://www.who.int/cancer/palliative/en/>

- [Accessed 13th April 2013]
2. Calaminus G, Birch JR, Hollis R, Pau B, Kruger M. The role of SIOP as a platform for communication in the global response to childhood cancer. *Pediatric Blood & Cancer*. 2013;60:2080-2086.
 3. Worldwide Palliative Care Alliance and World Health Organisation. *Global Atlas of Palliative Care at End of Life*, London; 2014.
 4. Amery J, Ngidi N, Rose C, Cunningham C, Horne C, Ganca L. Psychosocial and family care. In: Amery J (ed). *Children's palliative care in Africa*. New York. Oxford University Press Inc. 2009; 227-247.
 5. Hosoda T. The impact of childhood cancer on family functioning: A review. *Graduate Student Journal of Psychology*. 2014;15: 18-30.
 6. Manicom C. Psychosocial cancer care. There is more to cancer care than medical management. *CME*. 2010;28:58-63.
 7. Kohlsdorf M, Costa AL. Psychosocial impact of pediatric cancer on parents: A literature review. *Paidéia*. 2012;22:119-129.
 8. Hocking MC, Kazak AE, Schneider S, Barkman D, Barakat L, Deatrick JA. Parent perspectives on family-based psychosocial interventions in pediatric cancer: A mixed-methods approach. *Support Care Cancer*. 2014;22:1287–1294.
 9. Kazak AE, Simms S, Barakat L, Hobbie W, Foley B, Golomb V, Best M. Surviving cancer competently intervention program: A cognitive-behavioral and family therapy intervention for adolescent survivors of childhood cancer and their families. *Family Process*. 1999;38:175-191.
 10. Marcus J. Psychosocial issues in pediatric oncology. *The Ochsner Journal*. 2012;12: 211-215.
 11. Legal notice: Federal Republic of Nigeria Official Gazette No 2, Abuja 15th May 2009 Vol. 96. Page B 39- 40. Legal Notice on Publication of 2006 Census Final Results.
 12. Onwujekwe O, Hanson K, Uzochukwu B. Examining inequities in incidence of catastrophic health expenditures on different healthcare services and health facilities in Nigeria. *PLoS One*. 2012;7: e40811.
 13. Oyedeji GA. Socioeconomic and cultural background of hospitalized children in Ilesha. *Nig J Paediatr*. 1985;12:111-117.
 14. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3:77-101.
 15. Renner LA, McGill D. Exploring factors influencing health-seeking decisions and retention in childhood cancer treatment programmes: Perspectives of parents in Ghana. *Ghana Med J*. 2016;50:149–156.
 16. Buckle GC, Collins JP, Sumba PO, Nakalema B, Omenah D, Stiffler K, et al. Factors influencing time to diagnosis and initiation of treatment of endemic Burkitt Lymphoma among children in Uganda and western Kenya: A cross-sectional survey. *Infectious Agents and Cancer*. 2013;8:36. DOI: 10.1186/1750-9378-8-36
 17. Naidoo D, Gurayah T, Kharva N, Stott T, Trend SJ, Mamane T, et al. Having a child with cancer: African mothers' perspective. *South African Journal of Occupational Therapy*. 2016;46:49-54.
 18. Macaskill A, Monach JH. Coping with childhood cancers: The case for long-term counselling help for patients and their families. *British Journal of Guidance & Counselling*. 1990;18(1).
 19. Mostert S, Sitaesmi MM, Gundy CM, Janes V, Sutaryo, Veerman AJP. Comparing childhood leukaemia treatment before and after the introduction of a parental education programme in Indonesia. *Arch Dis Child*. 2010;95:20–25.
 20. Jithoo V. To tell or not to tell; the childhood cancer conundrum: Parental communication and information-seeking. *South African Journal of Psychology*. 2010;40: 351-360.
 21. Ribiero RC, Pui CH. Improving childhood cancer treatment in developing countries. *New Engl J Med*. 2005;352:2158-2160.
 22. Sint Nicolaas SM, Schepers SA, Hoogerbrugge PM, Caron HN, Kaspers GJL, van den Heuvel-Eibrink MM, et al. Screening for psychosocial risk in Dutch families of a child with cancer: Reliability, validity, and usability of the psychosocial assessment tool. *Journal of Pediatric Psychology*. 2016;41(7):810–819.
 23. Kazak AE, Barakat LP, Hwang W, Ditaranto S, Biros D, Beele D, et al. Association of psychosocial risk screening in pediatric cancer with psychosocial services provided. *Psycho-Oncology*. 2011;20:715–723. DOI: 10.1002/pon.1972
 24. Last BF, Grootenhuis MA. Emotions, coping and the need for support in families

- of children with cancer: A model for psychosocial care. *Patient Education and Counseling*. 1998;33(2):169-179.
25. Speechley KN, Noh S. Surviving childhood cancer, social support, and parents' psychological adjustment. *Journal of Pediatric Psychology*. 1992;17(1):15-31.
26. Ussher J, Butow P, Wain G, Hobbs K, Smith K, Stenlake A, et al. Research into the relationship between type of organisation and effectiveness of support groups for people with cancer and their Carers; 2005.

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