



WESTERN NIGERIA JOURNAL OF MEDICAL SCIENCES (WNJMS)

**KNOWLEDGE, BELIEFS, AND HEALTH-SEEKING BEHAVIOUR OF
CAREGIVERS OF CHILDREN WITH MALIGNANCIES**

KNOWLEDGE, BELIEFS, AND HEALTH-SEEKING BEHAVIOUR OF CAREGIVERS OF CHILDREN WITH MALIGNANCIES

Adefehinti O^{1,2}, Adeniyi OA¹, Kowobari ED³

1. Paediatric Haematology/Oncology unit, Department of Paediatrics, Obafemi Awolowo University Teaching Hospitals complex, Ile-Ife, Nigeria.
2. Department of Paediatrics and Child Health, Obafemi Awolowo University, Ile-Ife, Nigeria.
3. Department of Zoology, Obafemi Awolowo University, Ile-Ife, Nigeria.

Correspondences to: Adefehinti O., Department of Paediatric and Child Health, Obafemi Awolowo University, Ile-Ife, Osun State, Nigeria. **E-mail:** adefehintiolufemi@gmail.com; **Tel:** +234-8038065842

ABSTRACT

Introduction: Cancer remains one of the foremost causes of mortality globally, with an estimated 13.1 million deaths projected for 2030. The disease is not confined to the adult population but also affects children. Still, there is a significant lack of awareness and limited available information regarding paediatric cancers in low- and middle-income countries. This study assesses the knowledge, belief and health-seeking behaviour of caregivers who presented with children with malignancies at the Obafemi Awolowo University Teaching Hospitals Complex.

Methods: After informed consent was obtained, 176 caregivers of consecutive children below 15 years of age diagnosed with malignancies were administered a semi-structured, pretested, and validated questionnaire. Data were analysed using Statistical Product and Service Solution version 20, Chicago, Illinois, USA.

Results: Most caregivers (83.5%) lacked knowledge about childhood malignancies, with only 16.5% showing awareness, and 73.3% believed the condition was not curable. There was a statistically significant association between the caregivers' awareness about childhood malignancy and their level of education ($p=0.007$) and

monthly income ($p=0.022$), between the caregiver's place of first consultation and level of education ($p=0.000$).

Conclusion: Most caregivers are unaware of childhood malignancies, and those who are informed lack comprehensive knowledge. There is a need for public enlightenment nationwide to improve caregivers' understanding and awareness, enhance positive health-seeking behaviours, and promote early presentation, which has significant implications for improving treatment outcomes and survival rates of childhood malignancies.

Keywords: Knowledge, Belief, Caregiver, children, Malignancies.

INTRODUCTION.

Cancer remains one of the foremost causes of mortality globally, responsible for approximately 7.6 million deaths (13% of total deaths) in 2008, and this number is expected to increase, with an estimated 13.1 million deaths projected for 2030.¹ A further estimation in 2018 by the World Health Organisation (WHO) predicts that by 2040, there will be an increase to 29.5 million new cancer diagnoses and 16.5 million cancer-

related deaths annually.² The WHO estimates that, notably, in 2008, 70% of all cancer-related deaths occurred in low- and middle-income countries (LMICs).³ The disease is not confined to the adult population but also affects children, although there is a significant lack of awareness and limited available information regarding paediatric cancers in LMICs.⁴ Recently, there has been a marked increase in the incidence of childhood cancers worldwide, with developing countries contributing to approximately 60-80% of cases.⁵ It is estimated that 200,000 children are diagnosed with cancer annually in LMICs.⁵ This rising incidence is likely attributable to advancements in diagnostic techniques, increased community awareness, and heightened exposure to environmental risk factors.⁶

Given these trends, improving knowledge about paediatric cancers, recognising early symptoms, and encouraging timely hospital presentation, diagnosis, and treatment are crucial.⁷ Early intervention may improve treatment outcomes, reduce the need for intensive therapies in advanced disease stages, and ultimately lower mortality rates.⁷ Treatment outcomes for paediatric cancer have significantly improved, especially in high-resource settings, but remain suboptimal in resource-limited environments.⁸

Parents and guardians play a pivotal role in ensuring favourable outcomes in a child's cancer care.⁹ This starts with them being aware of its occurrence in children, which precedes their role in timely presentation to the appropriate quarter.¹⁰ Their role in the timely presentation of the disease is critical, as delays in seeking hospital care can lead to adverse outcomes.¹¹ Delayed presentation is a significant factor contributing to poor cancer outcomes in children in developing countries.¹¹ This delay is often linked to caregivers' inability to recognise early disease signs, general ignorance regarding the prevalence of paediatric cancers, and financial constraints.¹² Furthermore, the choice of treatment modalities by caregivers, often influenced by their level of knowledge about the patient's disease, has also impacted

outcomes.¹³⁻¹⁵ Many caregivers may resort to spiritual or traditional remedies, delaying hospital presentation until the disease progresses to a critical stage.¹⁶ Even after seeking hospital care, caregivers often face additional challenges, including financial burdens, the need to assist with daily activities, making critical decisions in collaboration with oncologists, and providing emotional support.¹⁷⁻¹⁹ This study, therefore, sets out to assess the knowledge of caregivers of children who had malignancies at first presentation and evaluate the likely implications of their level of awareness.

METHODS

This was a descriptive cross-sectional study carried out in the children's Emergency and Paediatric Oncology wards of the Obafemi Awolowo University Teaching Hospitals Complex with permission from the Ethics and Research Committee (ERC/2021/10/11). A semi-structured, pretested and validated questionnaire through a pilot study was administered to one hundred and Seventy-Six caregivers of consecutive children below 15 years of age admitted and later diagnosed with malignancies after informed consent was taken from such caregivers. Questions were asked to assess the caregiver's knowledge and health-seeking behaviour during the counselling session.

The semi-structured questionnaires contained several closed-ended questions, and responses were compiled to yield a score (a score of zero meant no knowledge, a score of 1 to 9 for the questions meant poor knowledge, and a score of greater than 10 for all the questions meant good knowledge).²⁰

The semi-structured questionnaire contained three sections; the first section was on the sociodemographic characteristics of the caregivers, including age, occupation, level of education, and monthly income in naira. The second section included questions to assess the beliefs and knowledge of the caregivers on the causes, treatment modalities, and duration

of treatment of childhood cancers; correct answers were scored one and others zero. All caregivers found to have poor knowledge or no knowledge were duly counselled by the oncology team. The third section treated the health-seeking behaviour of caregivers, which was assessed based on the place of first consultation after noticing symptoms and the duration of the child's symptoms before hospital presentation. Subjects were followed up for the duration of treatment. Data was analysed using Statistical Product and Service Solution version 20, Chicago, Illinois. USA. The sociodemographic variables of respondents were presented using frequency tables and charts. Bivariate analysis was done as appropriate to find the association between variables using Pearson's chi-square. Significant p-value was taken as < 0.05 at a 95% confidence interval.

RESULTS

Of the 176 caregivers interviewed, male caregivers were slightly more represented than female caregivers. Most caregivers fell within the 40–49 age range, with only 4.5% of the family earning above \$126 per month (Table 1).

The majority of caregivers (87.5%) were unaware of the causes of cancer in children, while 73.5% believed it was incurable, and nearly 90% lacked knowledge about survival outcomes (Table 2). Caregivers' initial point of consultation at the onset of symptoms and their first source of information about childhood cancers are shown in figure 1 and 2 respectively.

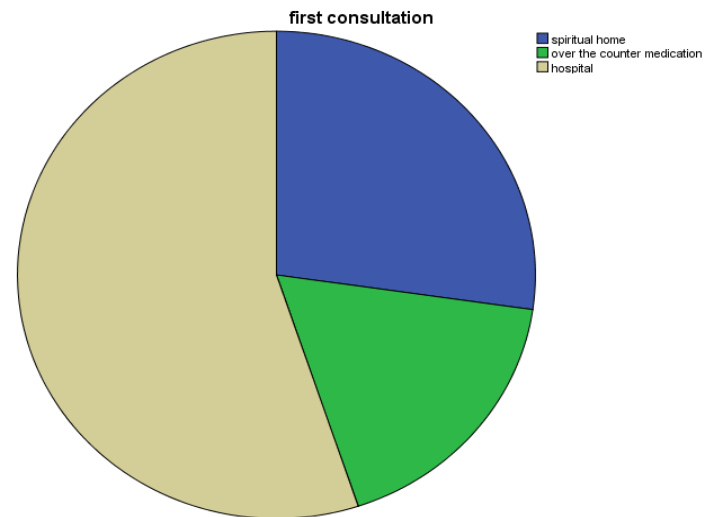
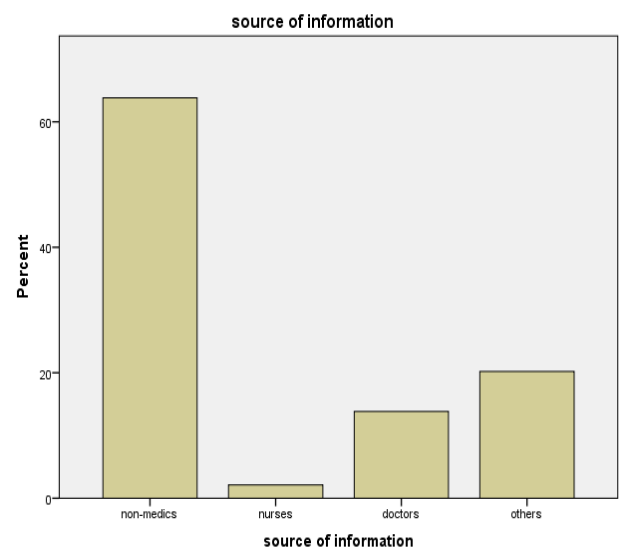
Among the diagnosed malignancies, Acute Lymphoblastic Leukaemia and Wilms' tumour were most common. The median time to hospital presentation was 18 days (IQR 7–30 days), with significant variation across cancer types. A strong association was found between the type of malignancy and duration before presentation ($p=0.001$) (Table 3).

Table 1: Sociodemographics of Caregivers

	n=176(%)
Age in years	
20-29	6(3.4)
30-39	66(37.5)
40-49	70(39.8)
>50	34(19.2)
Sex	
Male	101(57.4)
Female	75(42.6)
Monthly Family Income (Dollars)	
<32	74(42.0)
32-63	55(31.3)
>63	39(22.2)
>126	8(4.5)
Level of Education	
No formal education	8(4.5)
Some primary	7(4)
Complete primary	14(8)
Some secondary	17(9.7)
Complete secondary	56(31.8)
Tertiary	74(42.0)
Occupation	
Farming	17(9.7)
Civil servant	24(13.6)
Artisan	30(17)
Trader	72(40.9)
Others	33(18.8)
Ethnicity	
Yoruba	149(84.7)
Igbo	6(3.4)
Hausa	3(1.7)
Others	18(10.2)
Religion	
Christianity	116(65.9)
Islam	58(33.0)
Traditional	2(1.1)
Marital Status	
Single	4(2.3)
Married	145(82.4)
Divorced	10(5.7)
Widowed	12(6.8)
Separated	5(2.8)

Table 2: Beliefs of Caregivers About Cancer in Children

	Frequency n=176 (%)
Knowledge	
No	147(83.5)
Yes	29(16.5)
Knowledge Status of Caregivers that are Aware (n=29)	
Poor	21(72.4)
Good	8(27.6)
Causes	
No idea	154(87.5)
Spiritual	2(1.1)
Exposure to carcinogens	3(1.7)
Diet related	8(4.6)
Infection related	3(1.7)
Inherited/ genetic	6(3.4)
Effective Treatment	
Others	61(34.7)
Medical	25(14.2)
No idea	90(51.1)
Curability	
No	129(73.3)
Yes	21(11.9)
No idea	26(14.8)
Child's Chances of Survival	
No idea	157(89.2)
No	10(5.7)
Yes	9(5.1)
Aims of Treatment	
No idea	152(86.4)
Symptomatic	2(1.1)
Palliative	1(0.6)
Curative	21(11.9)

**Figure 1: Caregivers' First Place of Consultation at Symptoms Presentation****Figure 2: Caregivers' first source of information**

Statistical analysis revealed significant associations between caregiver knowledge and their occupation ($p=0.045$), as well as between caregiver education and both awareness ($p=0.007$) and place of first consultation ($p=0.001$). Income level was also significantly linked to awareness ($p=0.022$) (Table 4).

DISCUSSION

The unusually high number of male caregivers observed in this study, contrary to the conventional trend where females predominantly undertake caregiving roles, was attributed to the facility oncologist's routine policy of primarily engaging with male caregivers under defined circumstances.

Table 3: Reported Cancer Cases in Children of Caregivers and Mean Duration before Presentation

Cancer Cases in Children	Frequency (n=176)%	Mean Duration before Presentation (days)±SD
Burkitt lymphoma	18(10.2)	37.39±50.89
Acute Lymphoblastic Leukaemia	34(19.3)	16.18±14.27
Wilms tumour	31(17.6)	21.77±24.29
Rhabdomyosarcoma	12(6.8)	59.50±106.03
Hodgkin lymphoma	6(3.4)	134.33±124.57
Non-Hodgkin lymphoma	29(16.5)	68.93±140.04
Retinoblastoma	8(4.5)	40.25±42.04
Primitive Neuroectodermal Tumour	4(2.3)	38.00±44.44
Germ Cell Tumour	5(2.8)	68.00±112.97
Acute Myeloblastic Leukaemia	9(5.1)	5.33±4.30
Chronic Myelocytic Leukaemia	12(6.8)	120.67±221.34
Ewing Sarcoma	1(0.6)	365.00±0.00
Nasopharyngeal Carcinoma	1(0.6)	1.00±0.00
Neuroblastoma	2(1.1)	25.50±6.36
Malignant teratoma	3(1.7)	25.00±31.00
Colonic Cancer	1(0.6)	11.00±0.00

n: number of participants tested, SD: standard deviation; df: degree of freedom, χ^2 : Fisher's Exact chi square, statistically significant $p<0.05$; ($\chi^2 = 515.179$, $df=360$, $p=0.001$).

Table 4: Bivariate Analysis

Parameters	Caregivers' Level of Knowledge (No Idea, Poor and Good)		
	χ^2	df	p value
Monthly income	11.673	6	0.700
Occupation	15.824	8	0.045
Level of Education	12.828	10	0.245
Place of First Consultation (Spiritual House, Over the Counter and Hospital)			
	χ^2	df	p value
Monthly Income	7.184	6	0.304
Occupation	14.281	8	0.075
Level of Education	31.704	10	0.001
Caregivers' Awareness of Cancer (No and Yes)			
Monthly Income	9.642	3	0.022
Occupation	9.025	4	0.060
Level of Education	15.845	5	0.007

df: degree of freedom, χ^2 : Fisher's Exact chi square, statistically significant $p<0.05$

This strategy is likely to enhance team motivation and contribute to more coordinated and comprehensive patient care outcomes. Additionally, the mean age, predominant age range, and marital status of caregivers in this study align with previous reports in similar contexts.^{21,22}

In terms of socioeconomic status, only 4.5% of caregivers reported a monthly income exceeding \$126, indicating that the majority fall within low-income brackets; an expected outcome given the country's current economic challenge. Notably, monthly income showed a statistically significant association with caregivers' awareness of childhood cancer. This aligns with findings from studies conducted in more resource-rich settings, where children from higher-income families were more likely to be informed, report symptoms early, and seek medical attention promptly compared to those from lower-income households.²³ Such disparities are likely influenced by factors including access to health information, affordability of care, and socioeconomic barriers. Promoting early symptom recognition and reducing delays in seeking care among low-income families will require ensuring affordable treatment options and minimising indirect costs.

The hospital's proximity to several tertiary institutions may explain why most caregivers have attained higher education, which should, in principle, enhance their understanding of paediatric cancers. This assumption is supported by the strong, statistically significant association observed between caregivers' level of education and their awareness of cancer. Furthermore, the predominance of traders among caregivers suggests that occupation plays a role in determining exposure to health-related information within the community. This was confirmed by the significant association between caregivers' level of knowledge and their occupational category. As such, traders may represent a critical demographic for future childhood cancer awareness campaigns, as the majority fall into this category.

The majority of respondents had either poor knowledge or no knowledge at all about childhood cancers, a finding consistent with studies in other resource-limited settings.^{24, 25} Moreover, 63.8% of those who possessed some knowledge about childhood cancer derived it from non-medical sources. This highlights the necessity for enhanced community awareness and public education through mass media and active community involvement by engaging local stakeholders to reach individuals of low socioeconomic status who may not have access to reliable information.

Caregivers' initial point of consultation was significantly associated with their level of education, with over half choosing to seek help at a hospital. This trend aligns with findings from other Nigerian studies, where higher educational attainment among caregivers has been linked to improved recognition of danger signs and prompt health-seeking behaviour.²¹ Nevertheless, delayed presentation remains common among caregivers in Nigeria, often contributing to poor outcomes for conditions that might otherwise be curable if addressed early.¹³ Interestingly, children diagnosed with haematological malignancies were more likely to present earlier than those with solid tumours, likely due to more acute symptoms such as anaemia, bleeding tendencies, and persistent fever. This observation supports the significant association found between cancer type and the duration of symptoms before hospital presentation.

CONCLUSION

This study revealed a significant gap in knowledge, the persistence of misconceptions, and inadequate health-seeking behaviours among caregivers of children with malignancies. These insights highlight an urgent need for well-structured public health initiatives that promote accurate awareness and dispel prevalent myths about paediatric cancers. Community-based education and widespread sensitisation efforts are vital in equipping caregivers with dependable information. Enhancing

caregivers' understanding and fostering prompt access to appropriate medical care will greatly contribute to earlier diagnosis, improved treatment adherence, and better survival outcomes for affected children.

REFERENCES

1. Bray F, Moller B. Predicting the future burden of cancer. *Nat Rev Cancer* 2006; 6(1):63-74.
2. Shah SC, Kayamba V, Peek RM Jr, Heimbürger D. Cancer Control in Low- and Middle-Income Countries: Is It Time to Consider Screening? *J Glob Oncol*. 2019; 5:1-8.
3. Akinde OR, Phillips AA, Oguntunde OA, Afolayan OM. Cancer mortality pattern in lagos university teaching hospital, lagos, Nigeria. *J Cancer Epidemiol*. 2015; 842032.
4. Stefan C, Bray F, Ferlay J, Liu B, Maxwell Parkin D. Cancer of childhood in sub-Saharan Africa. *Ecancermedicalscience*. 2017; 11:755.
5. Kellie S, Howard S. Global child health priorities: What role for paediatric oncologists? *Eur J Cancer*. 2008; 44:2388-2396.
6. Sloan FA, Gelband H (eds). Washington (DC): National Academies Press (US). Institute of Medicine (US) Committee on Cancer Control in Low- and Middle-Income Countries. Cancer Control Opportunities in Low- and Middle-Income Countries. PMID 2007: 21595106.
7. Mullen CJR, Barr RD, Franco EL. Timeliness of diagnosis and treatment: the challenge of childhood cancers. *Br J Cancer*. 2021; 125(12):1612-1620.
8. Gupta S, Howard SC, Hunger SP, Antillon FG, Metzger ML, Israels T, et al. Treating childhood cancers in low- and middle-income countries. In: Gelband H, Jha P, Sankaranarayanan R (eds). *Cancer: Disease Control Priorities*. 3. Washington, DC: World Bank; 2015.
9. Renner LA, Segbefia C, Amankwah, E. Using data to improve childhood cancer care in low and low-middle income countries, Ghana as an example. *Pediatr Hematol Oncol J*. 2018; 3(4):99-101.
10. Lewandowska A. The Needs of Parents of Children Suffering from Cancer—Continuation of Research. *Children*. 2022; 9:144.
11. Lombe DC, Mwamba M, Msadabwe S, Bond V, Simwinga M, Ssemata AS, et al. Delays in seeking, reaching and access to quality cancer care in sub-Saharan Africa: a systematic review. *BMJ Open*. 2023; 13:13(4):e067715.
12. Uribe-Ortiz LV, Garza-Ornelas BM, Vázquez-Fernández AC, Castorena-Torres F, Rodríguez-De-Ita J. Exploring knowledge of parents and caregivers on cancer symptoms in children: an observational study regarding the need for educational tools and health promotion in low- and middle-income countries. *BMC Pediatr*. 2022; 22(1):638.
13. Joseph AO, Balogun OD, Akinsete A, Habeebu M, Jimoh M, Lasebikan N, et al. Early Detection of Paediatric Cancer: Equipping Primary Health-Care Workers in Nigeria. *Niger J Med*. 2022; 31:41.
14. Dye TD, Bogale S, Hobden C, Tilahun Y, Hechter V, Deressa T, et al. Complex care systems in developing countries: Breast cancer patient navigation in Ethiopia. *Cancer*. 2010; 116:577-585.
15. Brasme JF, Morfouace M, Grill J, Martinot A, Amalberti R, Bons-Letouzey C, et al. Delays in diagnosis of paediatric cancers: A systematic review and comparison with expert testimony in lawsuits. *Lancet*. 2012; 13:e445-459.
16. Merriam, S Muhamad M. Roles Traditional Healers Play in Cancer Treatment in Malaysia: Implications for Health Promotion and Education.

- Asian Pacific journal of cancer prevention. APJCP. 2013; 14:3593-3601.
17. Machaki DVW, Mutisya AK, Mutinda J, Oluchina S, Gatimu SM. Challenges and coping strategies among caregivers of children with cancer receiving care at a national referral hospital in Kenya. BMC Palliat Care. 2024; 23:242.
18. Glajchen M. Physical Well-Being of Oncology Caregivers: An Important Quality of Life Domain. SON. 2012; 28(4):226.
19. Kent EE, Rocque GB, Azuero A, Harrell ER, Gazaway S, Reed RD, et al. Family caregiver roles and challenges in assisting patients with cancer treatment decision-making: Analysis of data from a national survey. Health Expectations: IJHPM. 2023; 26(5):1965.
20. Fabiyi AK, Kolawole BA, Adefehinti O, Ikem RT. The impact of knowledge, attitude, practice, and beliefs of type 2 Nigerian diabetic patients on drug compliance. IDF. 2002; 12(1):15-17.
21. Aigbokhaode AQ, Isah EC, Isara AR. Health seeking behaviour among caregivers of under-five children in Edo State, Nigeria. SEEJPH. 2015; 3:1-10.
22. Elsayy M, Moustafa G, Ismail G, Magdy H, Man G. Knowledge and Home Practices of Caregivers Having Children with Leukemia Attending National Cancer Institute, Cairo University. Med J Cairo Uni. 2013; 81:601-608.
23. Ilowite MF, Al-Sayegh H, Ma C, Dussel V, Rosenberg AR, Feudtner C, et al. The relationship between household income and patient-reported symptom distress and quality of life in children with advanced cancer: A report from the Pediquet study. Cancer. 2018; 124(19):3934-3941.
24. Rekha RN, Kanwaljit GM. Descriptive Study to Assess the Level of Knowledge regarding Leukemia among Caregivers of Leukemia Patients in Selected Hospitals of District Mohali, Punjab. IJHSR. 2018; 8(11):7.
25. Geetha. C. Knowledge on Leukemia, The Stress And Coping Strategies of Mothers With Leukemic Children Undergoing Treatment in a Selected Cancer Institute, India . IJRSR. 2015; 6(5):4192-4196.