Original Article

Early Detection of Paediatric Cancer: Equipping Primary Health-Care Workers in Nigeria

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Abstract

Background: Paediatric cancer patients in Nigeria continue to arrive at specialist centers with advanced-stage disease. The reasons for this are myriad, not least of which are delays in detection, diagnosis, and referral for treatment. While delayed presentation has often been reported from the perspective of delays from caregivers' decisions, institutional deficiencies in the health care system may account for an unmeasured portion of the factors leading to delayed presentation. This project centered around training of health-care professionals at community level to detect potential paediatric cancer signs and refer appropriately. **Aim:** The aim of the study is to access the immediate impact of training on early detection and referral of possible paediatric cancer cases in the community and primary level health care workers and professionals in the Southwest Nigeria. **Materials and Methods:** This was a retrospective review of the training impact in three South-Western states in Nigeria. Scores before and after the training were analyzed using the IBM SPSS statistics, version 23 (IBM, Armonk, NY, USA). **Results:** A total of 732 primary health care workers were trained. In the pre assessment evaluations, 44.8% of participants reported that cancer did not occur in children, 47.2% did not know any referral pathway for a child suspected of cancer. The post training assessment indicated an improvement in participants' understanding of common paediatric cancers types and how to refer a suspected case for specialist diagnosis and attention. Mean scores before and after the training were 3.5/15 and 12.5/15, respectively. **Conclusion:** Training health-care professionals working at the community level can have an immediate and measurable impact on early detection and referral for paediatric cancers, as seen by the difference in pre training and post training assessment scores. There remains a need for continuous training to ensure early referral and ultimately increase survival indices of children diagnosed with cancer in Nigeria.

Keywords: Community-based health workers, early detection, paediatric cancer

Introduction

Paediatric cancer international estimates that, globally, ten children die from cancer and cancer-related causes every hour, 250 children every day, and over a hundred thousand every year.[1] Current data also indicate a disproportionate morbidity and mortality burden in low-and middle-income countries (LMICs) like Nigeria.[2] It has been reported that although paediatric cancer incidence rates are relatively low in LMICs compared to high-income countries, only a small proportion of these children receive timely and appropriate care, resulting in significantly higher mortality rates.[3] In high-income countries, survival rates for many paediatric cancers are currently as high as 80%–90%. By comparison, paediatric cancer survival rates in Nigeria continue to hover around 30%, with the most common paediatric cancer types being leukemia, lymphoma, retinoblastoma, Wilms' tumor (nephroblastoma), osteosarcoma, and neuroblastoma.[4,5]

Much work has been done to identify the causes and contributing factors to the persistently lower paediatric cancer

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survival rates seen in Nigeria and other developing countries. Poor health-seeking behavior, geographic inaccessibility, financial unaffordability of care, infrastructural deficiencies, deficient diagnostic capability and equipping of health workers, and specialist care unavailability have been documented as some of the causes.[6,7] Several studies have also reported the role of delayed presentation in impacting survival rates.[8] Often, these studies have quite accurately blamed delayed presentation on factors such as lack of awareness, poor health-seeking behavior,[9] stigma, and sociocultural/religious beliefs of patients,[10] or in the case of paediatric patients, the parents, or caregivers.[11,12] The authors, however, hypothesize that an unexplored reason for delayed presentation may be gaps in the health-care strata that create delays or missed opportunities for detection and diagnosis (missed diagnosis) or lead to inaccurate diagnosis being made (misdiagnosis). These factors may also account for an unmeasured portion of the causes of persistent delayed presentation.[13,14]

Increasingly, our experience indicates that even a parent who may not seek care for a symptom they are experiencing would tend to seek care for their child. It is becoming increasingly evident that children with cancer often do present earlier in the course of their disease to varying primary and community level health-care facilities.[15] Unfortunately, as these facilities do not enjoy the highly specialized infrastructure and/or personnel required to diagnose complicated conditions such as cancer accurately, they do what they can do. Usually, they end up delivering generic and conservative treatments for common infectious diseases like malaria or typhoid fever, often repeatedly, thereby missing the diagnosis of cancer, prolonging the time to accurate diagnosis, exhausting the patient financially, and delaying the commencement of life-saving intervention.[16,17] This combination of wrong diagnosis, ineffective treatments, out-of-pocket health-care expenditure and the passage of time may be a lethal mix negatively impacting survival indices as a yet unmeasured but potentially significant factor.[18] Arguably, as global awareness of cancer increases over time, health-seeking behaviors are also evolving and improving; as such, we hypothesize that investment of time, energy, resources, and policy changes into the empowerment of health care professionals at the primary and community levels, could be the next logical step in improving paediatric cancer survival in LMICs like Nigeria.[19,20]

The United States Labour Force defines community-based health-care workers as a diverse group of health-care personnel who work outside of the confines of fixed health-care institutions, aid individuals and communities in adopting health-improving lifestyle changes and improve health-seeking behavior. These cadres of health-care workers do not receive the intensive medical training that doctors and specialist nurses do, only limited training to aid in delivering their community-based tasks.[21] Despite their limited training, community-based health workers are widely recognized as critical players in population-based interventional programs.[22] In the United States of America, community-based health workers were instrumental in improving women's health, reducing the spread of HIV/AIDS, hypertension, and cardiovascular disease control, diabetes screening, tuberculosis control, and more recently, cancer screening.[21] In Nigeria, community-based health-care workers were profoundly instrumental in the achievement of 80% coverage for vaccine-preventable diseases in 2013.[22] Several cadres of community-based health-care workers exist including Community Health Officers (CHOs), Community Health Extension Workers (CHEWs), and Junior CHEWs (JCHEWs).[23]

Tying into this network of community health-care workers is the primary health-care (PHC) system. The World Health Organization defines the PHC system as "the whole-of-society approach to health that aims at ensuring the highest possible level of health and well-being and their equitable distribution by focusing on people's needs and as early as possible along the continuum from health promotion and disease prevention to treatment, rehabilitation, and palliative care and as close as feasible to people's everyday environment."[24] In Nigeria, along with community-based health care workers, health-care professionals working at the primary level including private hospital doctors, nurses, and local pharmacists, represent the first port of call for many individuals in the community and attend to a wide array of cases. Their presence in the community, easy accessibility, and shorter or less convoluted protocols make these health-care workers preferable for many patients, parents, and caregivers.[25] Therefore, the involvement of health-care professionals at this level in the early detection and prompt referral of children and adolescents with possible signs or symptoms of cancer is a necessary systemic step in the improvement of paediatric cancer survival in Nigeria and other LMICs with similar resource constraints and health-care workforce to population ratios.[26] Further, in a region endemic for infectious disease, the ability to make the distinction between common infectious conditions such as malaria and a suspected case of cancer by having a high index of suspicion would be valuable to detection, early referral, diagnosis, treatment, and ultimately to survival. This study assessed the immediate impact of a training program on the early detection and referral of possible paediatric cancer cases in the community and primary level health care workers and professionals in Southwest Nigeria.

Materials and Methods

The study was a retrospective review of participants' responses recorded before and after training sessions conducted in February 2019, April 2019, and September 2019 for primary and community-based health-care workers in Ogun, Oyo, and Lagos State, respectively. Together these three states account for approximately 13% of the Nigerian population and are situated in Southwestern Nigeria. Lagos, Nigeria's former capital, is the most densely populated state and its urban and commercial capital.[27] The training sessions were held at major tertiary institutions in the state in collaboration with the participating states' ministries of health and PHC boards.

A total of three training sessions were held, with 732 participants recruited through convenience sampling, having met the inclusion criteria of being a health-care professional in active practice at a community or PHC center in a low to middle resource region. Specialist or professionals practising at tertiary or high-speciality centers who had received prior specialist training were excluded from the program. Study participants comprised community health workers, nurses, and medical officers working at primary health centers within the participating states. The training was held in collaboration with the ministries of health and PHC boards of the participating states to ensure that participants represented every region of the state.

The training addressed the most common paediatric cancers in Nigeria; hematologic cancers (Leukemias and Lymphomas), cancers of the eye and orbit (retinoblastoma and orbital Sarcomas), abdominal tumors (nephroblastoma and neuroblastoma) as well as bone tumors (osteosarcoma, Ewing sarcoma, and other bone tumors). The training program was conducted on a single day for each training, over an average of 8 h, with two 15-min breaks and one 30-min break. The curriculum was designed to deliver a basic understanding of common paediatric cancers encountered in Nigeria, teach the signs and symptoms of the common cancers, and disseminate a prototype algorithm called "The 5 Signs and 5 Questions Method" that would elicit some of the most common possible signs or symptoms of cancer or other illness requiring special attention in a child [Figure 1 and Figure 2]. The training emphasized "Detection Not Diagnosis," as centers in the community do not have the infrastructure, equipment, or personnel required to diagnose cancer. The training premise was for the health-care worker in the community to detect that a condition requiring more intensive evaluation or assessment is present and to refer that child for further evaluation or intervention without delay.

An assessment tool was administered to every participant before the training. The same tool was then administered after the training, and the pre-and post-training scores were recorded and analyzed. The assessment tool was divided into three sections; the first section collected sociodemographic (age, gender) and health care experience (role or position, years in role, total years in practice, qualifications) information of the participants. This section also collected information about each participant's center, the area served, number of patients (adult and paediatric seen), and common conditions treated. This first section also assessed the estimated number of suspected cancer cases seen or referred from the center over an annual period. The second section contained 15 questions assessing participants' knowledge of common paediatric cancers and their signs and symptoms. Participants could answer 'Yes, "No" "Do not know". Correct answers were assigned a score of "1," while incorrect answers or "Do not know" were assigned a score of "0." A total score out of a maximum of 15 for each participant was then generated. The third section assessed participants' knowledge of referral pathways for diagnostic or specialist intervention in suspected cases of cancer and any reasons for the failure of referral to specialist centers. Post training assessment using the same tool was conducted to assess the difference in responses before and after the training and analyze for any correlations between participants' history and assessment findings.

The training curriculum, course content, 5 Signs and 5 Questions algorithm, and assessment tools used in this project program were developed and pretested by a team consisting of a radiation oncologist, a paediatric oncologist, a public health physician, a nurse, and a statistician. The curriculum and tool were pretested among 20 community health workers in Lagos State, with modifications and corrections based on the preliminary results. Collected data were analyzed using the Statistical Package for the Social Sciences version 23 software (IBM Corp, Armonk NY, USA). $P < 0.05$ was considered statistically significant.

Ethical approval for this project was obtained from the Health Research and Ethics Committee of the Lagos University Teaching Hospital. Informed consent was sought and obtained from every participant before the assessment and training. Consenting participants participated in the pre training review, the training program, and the post training assessment. Approval for the project was also received from the participating states' ministries of health and PHC boards.

Results

A total of 732 health-care workers from 47 primary health centers in three states in South-Western Nigeria participated in this training program. Participants' mean age was 35.6 ± 5.4 years, ranging from 29 years to 54 years. The participants had been in health service for an average of 13 years, and in most cases, they reported that they were the first port of call for patients in their community. Almost half (41.5%) of the participants were nurses, CHEWs, JCHEWs, CHOs, and medical officers (doctors), making up the rest of the trainee population [Table 1].

At the pre training assessment, 44.8% of participants reported a lack of awareness of the possibility of a cancer diagnosis in children, this percentage reduced to 0% at the post training assessment. In addition, before the training, only 50.2% of participants indicated they believed a child could survive cancer; however, post training, 82.0% of participants reported paediatric cancers could have a good prognosis if detected early, diagnosed accurately, and treated promptly and adequately [Table 2].

Less than a quarter of participants (19.9%) reported having ever managed a suspected case of cancer. Reasons selected for not referring a child with recurrent illnesses or unclear diagnosis to specialist centers included "the participant's belief that children could not have cancer" (44.8%), not knowing where to refer (10.6%), the parent or caregiver refusal (3.6%), rumours of high treatment costs (4.2%), and fear of losing the patient (11.5%) [Figure 3].

There was no statistically significant association between the gender of respondents and the mean pre training assessment score ($F = 0.05$, $P = 0.943$). There was, however, a statistically significant association between the mean pre training assessment score and the position of the health care worker, with medical officers scoring the highest (mean of 6.3).($F = 164.511$, $P < 0.001$).

There was also a statistically significant association between the pre training mean assessment scores and location of practice, with participants in Oyo state scoring the highest (mean of 3.8) ($F = 9.109$, $P = 0.000$). Pre training, there was a statistically significant association between the age of the participant and assessment scores, with younger participants having significantly higher scores and older participants with lower scores ($P = 0.025$). In contrast, the number of years of experiences was not significantly associated with pre training assessment scores ($P = 0.451$).

There was a statistically significant association between the post training assessment scores and the position of health workers ($F = 6.700$, $P < 0.001$), with medical officers scoring the highest (mean score of 13.0) and JCHEWs scoring the lowest (mean score of 12.3). The location (state) of practice was also significantly related to the post training assessment scores ($F = 29.242$, $P < 0.001$). Neither age of respondent ($P = 0.262$) nor the number of years of practice ($P = 0.739$) were statistically significantly associated with post training assessment scores.

The overall mean assessment scores, pre-and post-training, were 3.5 and 12.5 out of a total of 15, respectively [Table 2], indicating a significant improvement in the knowledge level

Table 1: Sociodemographic characteristics of respondents (*n*=732)

Variable	*n* (%)
Age (mean±SD)	35.6±5.4
Sex	
Female	525 (71.7)
Male	207 (28.3)
Location	
Oyo	305 (41.7)
Ogun	224 (30.6)
Lagos	203 (27.7)
Years of practice	
Mean±SD	12.6±5.4
Range (years)	3-35
Position	
Nurses	304 (41.5)
Medical officers	96 (13.1)
Community health extension workers	198 (27.0)
Junior community health extension workers	107 (14.6)
Community health officers	27 (3.7)

SD: Standard deviation

Table 2: Training assessment

Variable (*n*=732)	Yes, *n* (%)	
	Pre training	Post training
Knowledge of childhood cancers		
Children can have cancer?	404 (55.2)	732 (100.0)
Children can survive cancer?	369 (50.4)	606 (82.0)
Recurrent febrile illness in a child could be caused by cancer?	112 (15.3)	698 (95.4)
Children can get cancer in the eye?	310 (20.2)	732 (100.0)
All childhood cancers present with a swelling/mass?	396 (54.1)	46 (6.3)
Swelling caused by cancer is always painful?	401 (54.8)	54 (7.4)
Cancer can cause bone pain in children?	108 (14.8)	587 (80.2)
Which of the following is a reason to suspect cancer in a child?		
Painless abdominal swelling or mass	105 (14.3)	715 (97.7)
One episode of very high fever	421 (57.5)	120 (16.4)
Discoloration of the pupil in dim light or the dark	115 (15.7)	730 (99.7)
Bone pain in a sickle cell patient	265 (36.2)	389 (53.1)
Which of these are risk factors of cancer in children		
History of cancer in one or both parents	318 (43.4)	732 (100.0)
History of a genetic condition in the child or a sibling	98 (13.4)	540 (73.8)
In which of these sites is cancer likely to occur in children?		
Breast	354 (48.4)	72 (9.8)
Prostate	308 (42.1)	56 (7.7)
Lungs	108 (14.8)	24 (3.3)
Kidneys	66 (9.0)	669 (91.4)
Blood	58 (7.9)	725 (99.0)
Lymph nodes	44 (6.0)	707 (96.6)
Brain and spinal cord	25 (3.4)	718 (98.1)
Mean score (range)	3.5±1.5 (2-11)	12.5±1.1 (9-15)

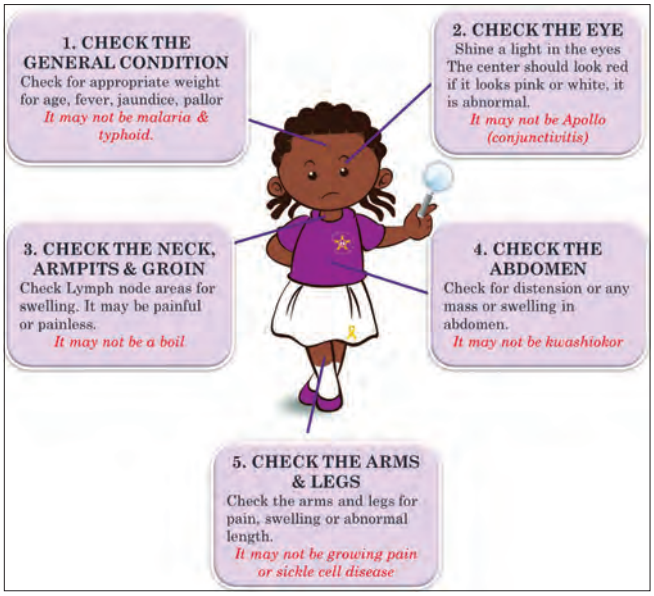

Figure 1: "The 5 Signs and 5 Questions Method" (5 Signs)

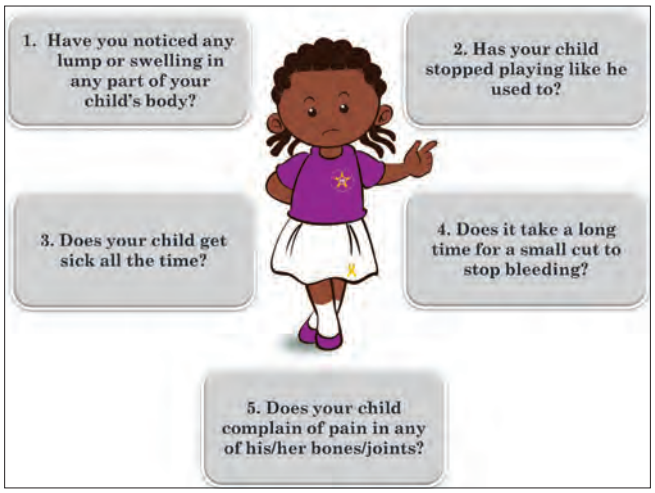

Figure 2: "The 5 Signs and 5 Questions Method" (5 Questions)

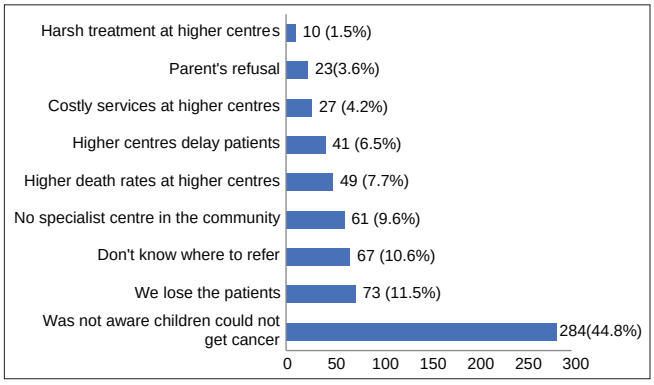

Figure 3: Reasons for non referral

of participants regarding signs and symptoms of cancer in children and referral pathways to decrease missed opportunities for detection and diagnosis.

Discussion

In order to improve paediatric cancer survival rates in Nigeria, early-stage presentation must match prompt and proper treatment. The right treatments will continue to fall short if children do not arrive at the paediatric oncologist until the disease is disseminated and incurable.

"In the United Kingdom, national guidelines and protocols are in place to ensure that a child suspected of having signs or symptoms of cancer sees an oncologist within two weeks.[28] By comparison, Nigeria has not implemented national guidelines or protocols regarding detection, referral, diagnosis, and care of paediatric cancer patients.[29] In a review by Dixon-Woods *et al*., initial complaints in children that prompted caregivers to seek help included nonspecific symptoms or signs ranging from gastrointestinal to the upper respiratory tract and constitutional complaints. In many cases, alternative reasons were initially considered for the child's reported symptoms, including infection, muscle strain, "growing pains," and "lying to get out of school. "The diagnosis of cancer was delayed, and definitive diagnosis were only arrived at over a median of 11 months.[30] Due to the nonspecificity of these initial symptoms, the health-care workers at the first point of presentation must have a high index of suspicion, understand the common presenting patterns, and the potential impact of delayed detection and referral, and vice versa.

In this study, before the training, almost half of the health care workers reported that they did not know or believe that cancer could occur in children. This finding may not bode well for the possible cases they may have encountered over their mean 13 years in health care. Although the incidence rates for paediatric cancers are relatively lower than those for adult cancers or infectious diseases in LMICs like Nigeria, it is significant that 55.2% of health-care workers at the community and primary levels reported a lack of awareness about the existence of cancer in the paediatric population.[31] It could then be imagined that a portion of these respondents would have over the course of their career encountered a child with signs and symptoms of cancer and either failed to refer the child appropriately or administered ineffective treatments for a wrong diagnosis; thereby missing an opportunity for early detection, and potentially worsening the prognosis. In a similar review by Slone *et al*. in 2016 of paediatric oncology training programs in Botswana, it was reported that 42.0% and 43.5% of participants did not know about paediatric oncology incidence and survival, respectively, before the training. By the end of the training, these numbers had reduced to 11.6% and 9.7%.[32] These findings are similar to those seen in this study.

Slone *et al*.[29] also reported similar findings in the referral process of health care workers before the training. In this study, pre training knowledge of referral processes for a suspected paediatric cancer case was adequate in only half (52.7%) of participants [Table 3]. This finding highlights the vital role of the referral chain in paediatric cancer care delivery in Nigeria.

Table 3: Referral process (*n*=732)

Variable	*n* (%)	
Have you ever suspected a child of cancer?		
Yes	146 (19.9)	
No	586 (80.1)	
Ever referred a child suspected of cancer for specialist care?		
Yes	98 (13.4)	
No	634 (86.6)	
Variable	**Pre training**	**Post training**
Would you refer a child suspected of cancer for specialist care?		
Yes	386 (52.7)	731 (99.9)
No	346 (47.3)	1 (0.1)
Where would you refer them?		
Private hospital	173 (23.6)	45 (6.1)
General hospital	198 (27.0)	362 (49.5)
Tertiary centres	90 (12.3)	302 (41.3)
Prayer house	88 (12.0)	12 (1.6)
Traditional healers	53 (7.2)	8 (1.1)
Home	68 (9.3)	0
I don't know	62 (8.5)	3 (0.4)

There is a need for continuous partnership between the PHC centers or other levels of care to ensure the smooth transfer of suspected paediatric cancer cases. Although the participants in this study reported that the primary reason for the lack of referrals was because they did not know that cancer could occur in children in the first place, the other reasons provided outlined the lack of definition and clarity on the referral processes and functioning at specialist centers for PHC providers in rural communities in Southwest Nigeria.

The factors that were significantly associated with mean assessment scores in participants before and after the training were the position of the health care worker and their location of practice. On average, medical officers scored higher than other health care workers, possibly due to previous training regarding paediatric cancer in the medical school curriculum. Additionally, the association between age and mean preassessment scores may be related to exposure to digital information regarding paediatric cancer that younger health workers may be privy to compared to the older ones. Although significant, it is unclear why there is an association between the study participants' location of practice and pre-and post-assessment mean scores. It may be related to community-based health workers' socio-cultural beliefs and practices from different states and how it impacts their clinical practice. Another potential reason may be state-level curricula for health-care worker training.

Since this was a pilot program, evaluating the training responses helped identify the gaps within the curriculum. For example, part of the training taught on the minor role that family history and hereditary or genetic conditions can play in the incidence of some cancer types, especially those seen in adults. Post training assessment, however, indicated that the concept was not adequately delivered, inadvertently overplaying the role of family history as a risk factor for paediatric cancers. As such, all participants reported family history in one or both parents as a risk factor of paediatric cancer during the post training assessment. While certain genetic conditions such as the presence of Down syndrome, von Hippel-Lindau syndrome or Beckwith-Wiedemann syndrome in child, sibling, or parent and germline mutations have been identified in the development of certain paediatric cancer types such as retinoblastoma; family history alone is often not a significant predictor of the development of paediatric cancer.[33,34] The training curriculum has subsequently been adjusted to correct this.

Furthermore, in the post training assessment, more than half of the participants noted that cancer should always with suspected in a child with sickle cell disease presenting with bone pain. This was an unexpected finding which could have been due to the reference to "bone pain" as a possible symptom for bone cancers such as osteosarcoma given during the training. Therefore, a need to clarify these distinctions in subsequent sessions has been noted and the curriculum duly adjusted to highlight the fact that other conditions could present with similar symptoms.

Although the training's immediate impact was significant, as indicated by the sharp difference in pre-and post-training evaluation scores (3.5–12.5), there is further need for an objective review of diagnostic and referral practices of participants following the training to ensure knowledge gathered is translated into practice and sustained over time. Centers where these community-based health workers practice could be followed up to note for a change (if any) in the incidence of referrals for suspected paediatric cancer cases before and following the training. Furthermore, continuous training and education programs for community and PHC workers may also reduce missed detection opportunities and ultimately improve children's survival indices with cancer in Nigeria.

To reduce the morbidity and mortality burden due to paediatric cancer in Nigeria and other LMICs, a holistic approach beginning at the community level is ideal. When these programs are accompanied by a concurrent strengthening of health-care systems at all levels, we may start to achieve increased survival rates for paediatric cancers, matching those seen in LMICs.

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Conflicts of interest

There are no conflicts of interest.

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