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Barriers to care for newly diagnosed children with cancer from Bungoma County after an awareness campaign: insights from parental interviews and registry data

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Abstract

Introduction Children in low- and middle-income countries face barriers to timely access to cancer care. Between January and June 2023, an awareness campaign in Bungoma County, Kenya, aimed to address this issue. This study describes sociodemographic and clinical characteristics of children diagnosed with cancer after the campaign, explores health-seeking behaviors and delays, and compares cancer referrals pre- and post-campaign.

Methods Parental interviews were conducted for all children newly diagnosed with cancer from Bungoma County at Moi Teaching and Referral Hospital between January 2023 and December 2024 using structured questionnaires. Hospital registry data from January 2014 to December 2024 were analyzed to compare referrals pre- and post-campaign (2014–2022 versus 2023–2024).

Results Following the campaign, 30 children were diagnosed with cancer (40% female, median age 5.5 years). Diagnoses included hematological cancers (23%), solid tumors (60%), rare solid tumors (7%), and brain tumors (10%), with 57% of solid tumors presenting at advanced stages. Delays were substantial: the median patient-, physician-, diagnosis-, treatment-, health system-, and total delays were 30, 104, 114, 6, 114, and 146 days, respectively. Barriers included the use of traditional medicine, cultural beliefs, financial strain, travel costs, lack of insurance, income loss, and fear. Annual referral rate before and after the campaign (2014–2022 versus 2023–2024) showed no statistically significant difference (Chi-square test, $p = 0.071$; Fisher's exact test, $p = 0.063$).

Conclusion The campaign did not increase cancer diagnoses, highlighting ongoing barriers to timely access to childhood cancer care. Addressing these barriers is essential for improving access to childhood cancer care. Factors such as healthcare worker strikes, supply shortages, and treatment seeking at other facilities may have contributed to the lower-than-expected numbers.

Keywords Awareness, Childhood cancer, Low- and middle-income countries

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Introduction

Childhood cancer affects more than 400,000 children worldwide annually. Most of these children live in low- and middle-income countries (LMICs) [1]. Nearly half of Kenya's population is aged below 18; this means that it is estimated that about 4000 children develop cancer annually (prevalence 0.002%) [2]. It is, however, projected that only a minority of these children are diagnosed and initiated on treatment in a referral hospital [3, 4]. Accessing comprehensive childhood cancer care remains one of the biggest challenges when addressing childhood cancer outcomes in LMICs [5]. The World Health Organization (WHO) Global Initiative for Childhood Cancer (GICC) was launched in 2018. It aims for a survival rate above 60% for children with common and curable types of cancer [6]. However, as long as only a minority of children with cancer receive a diagnosis resulting in adequate treatment, this goal will never be achieved.

The reason many children with cancer in LMICs, such as Kenya, will never be diagnosed is multifactorial. Contributors include both patient-related factors and healthcare worker-related factors that hinder timely access to care [7]. Parents' healthcare needs may not always be identified promptly, which can be influenced by varying levels of health literacy and a preference for traditional, complementary, and alternative medicine (TCAM) alongside or before engaging with conventional healthcare services [8–11]. Additionally, parents may not be able to afford healthcare services [9]. Regarding healthcare worker-related factors, a primary healthcare provider might not recognize childhood cancer upon first presentation in its early stages [12]. Since the disease is rare, many healthcare workers are not experienced in suspecting the disease. Moreover, many common childhood cancers resemble other more prevalent infectious diseases. For example, leukemia can easily mimic malaria or a viral infection [13]. A swollen lymph node can be confused for an infection rather than, for instance, Hodgkin lymphoma. Strange behavior and headaches can be mistaken for mental disorders instead of brain tumors [14]. The Kenyan national cancer control strategy strongly emphasized the importance of early detection and referral of children with cancer. Specifically, it stressed the importance of capacity building in primary care facilities and training [15].

A childhood cancer awareness campaign was implemented in Bungoma County, Western Kenya, in January 2023, aiming to train primary healthcare workers on the early recognition and adequate referral of children with cancer [16]. Posters and radio messages were distributed to raise awareness amongst the general public [14]. An extensive training program training all primary healthcare workers of affiliated community health units, dispensaries, and health centers was conducted.

The aim of this study, therefore, is to evaluate newly diagnosed children with cancer from Bungoma County after the implementation of the awareness campaign. The study aims to (1) describe sociodemographic and clinical characteristics of children newly diagnosed with cancer after the implementation of the childhood cancer awareness program from Bungoma County, (2) explore health-seeking behavior and delays in access to childhood cancer care amongst newly diagnosed children with cancer, and (3) compare referrals of children with cancer before and after implementation of the childhood cancer awareness campaign.

Methods

Study setting

This study was conducted at a tertiary care hospital, Moi Teaching and Referral Hospital (MTRH), in Eldoret, Kenya. Kenya is a lower-middle-income country in Africa. The country is split into 47 counties inhabited by over 42 tribes. The population was estimated to be 54,027,887 people, according to the 2019 census [17, 18]. Approximately *24,428,416* are under 18 years old. Bungoma County, where the childhood cancer awareness campaign was implemented, is a county in Western Kenya that hosts a population of 1,786,973 people, of which approximately 800,000 are children below 18 years of age. The majority are Christians and belong to the Bukusu, a sub-tribe of the Luyha community. Approximately 87% live in rural areas, while 13% reside in urban areas. The primary sources of income are farming and business. The majority registers for primary school, and half of the schooling population enrols in secondary school [19–21].

Primary and secondary care facilities offer healthcare services. The National Ministry of Health supervises the Kenyan healthcare system [22]. Health insurance is offered through the Social Health Insurance System (SHIF), which offers coverage for childhood cancer care. A decentralized system is in place, providing increased authority for decision-making, resource allocation, and healthcare management to county authorities. The Kenyan healthcare system comprises six distinct levels of care. The first three levels encompass primary healthcare and include community health units (Level 1), dispensaries (Level 2), and health centers (Level 3). Community health volunteers are affiliated with community health units and conduct health promotion in their respective communities. Secondary care consists of subcounty hospitals (level 4) and county hospitals (level 5). Tertiary care is offered in national referral hospitals (level 6). Two level 6 hospitals, MTRH and Kenyatta National Hospital, offer comprehensive childhood cancer care in Kenya [23, 24]. Annually, around 140 children from Bungoma County would be expected to develop cancer based on the global incidence of 15 per 100.000 [25].

The awareness campaign

Between January and June 2023, a childhood cancer awareness campaign was implemented in Bungoma County. The campaign included training for all healthcare providers in Level 2 and 3 facilities, as well as their affiliated community health volunteers. The training focused on recognizing the six common and curable types of cancer, as defined by the GICC [6], treatment modalities, the importance of early detection, the importance of health insurance registration, and finally, how to refer children suspected of having cancer in a timely manner. The program focused on the GICC-prioritized common and curable cancers, as these represent the most frequently occurring cancers with high potential for successful treatment when detected early [6].

Following the live training session, a self-paced learning program was made available to healthcare workers via SMS learning [16]. This SMS-learning program delivered seven modules per SMS, on the same topics as the live training session. Upon completing both the live training session and the seven SMS learning modules, healthcare workers obtained a certificate.

Additionally, posters displaying early signs and symptoms of childhood cancer were distributed to all primary care facilities and posted in waiting rooms for both patients and healthcare providers to be reminded of the warning signs [26]. Phone numbers of the pediatric oncology team at MTRH were written on the posters for easy communication on referrals. Finally, a radio campaign was conducted to reach the communities of Bungoma County.

Study design

This was a mixed-methods study that used both a prospective and retrospective approach to evaluate the impact of the awareness campaign. The prospective approach included parental interviews with the parents of children from Bungoma County at MTRH who were newly diagnosed with cancer after the start of the implementation of the childhood cancer awareness campaign in Bungoma County. Parental interviews were conducted using a structured questionnaire developed by a panel of experts from Kenya, the United States, and the Netherlands in pediatric oncology, informed by a review of the literature on delays in access to childhood cancer care [27–34]. (Supplementary file 1). Additionally, retrospective data were obtained from the hospital registry at MTRH to compare the number of referrals of children with cancer before and after the start of the awareness campaign.

Parental interviews

All children up to 14 years of age, referred from Bungoma County, confirmed to have childhood cancer, were eligible for inclusion starting from January 2023 up until December 2024. The research nurse monitored all referrals arriving from Bungoma County at MTRH and proceeded to an informed consent procedure prior to the parental interview. The interview was conducted in Kiswahili and consisted of a structured questionnaire that collected the following data: socio-demographic information, clinical details, delays, usage, and perceptions of both conventional medicine and TCAM, as well as barriers to referral. Regarding delays, we identified six distinct types: patient delay, physician delay, diagnosis delay, treatment delay, health system delay, and total delay [34]. Clinical data included sex, age, type of cancer, stage of cancer, and early death. Early death was defined as death within 42 days after diagnosis [35]. Stage of cancer was defined as low in solid tumors, stage 1 or 2, and as high in stage 3 and higher. Socio-demographic variables, including parental age, ethnicity, religion, occupation, and income, were collected to assess the representativeness of the referred patients in relation to the broader population of Bungoma County. Regarding the different types of delays, several questions were included to identify the causes of each type of delay. For patient delay: onset of symptoms, action upon onset of symptoms, usage of conventional medicine and TCAM, transportation challenges, health insurance status, beliefs about cancer. For physician delay: treatment for other illnesses, counselling on cancer, appropriate referral, counselling on SHIF. For diagnosis delay: action upon first presentation at MTRH. For treatment delay: the time from diagnosis to the start of treatment.

Comparison of referrals before and after the awareness program

Data on annual referrals of newly diagnosed children with cancer from Bungoma County to MTRH were extracted from the institutional registry for the period from 2014 to 2024. As the registry was established in 2014, this year marked the starting point for the pre-intervention period, which extended until December 2022. The post-intervention period was defined as January 2023, corresponding with the launch of the awareness program, through December 2024.

Statistical analysis

Data collection was done using Castor version 0.1.45. All data was anonymized using patient identifiers. Data management and analysis were conducted using *SPSS* version 26.0. Frequency distributions, medians, means, and standard deviations were calculated from the dataset to describe the data obtained from parental interviews on the characteristics of newly referred children with cancer. We compared the proportion of children with cancer referrals originating from the intervention province before and after the implementation of the intervention. The pre-intervention period was defined as 2014–2022, and the post-intervention period as 2023–2024. For each period, we calculated the proportion of referrals from the intervention province relative to the total number of referrals from all provinces combined.

To assess whether the observed change in proportions differed significantly between the two periods, we constructed a 2 × 2 contingency table (province of referral: intervention province vs. all other provinces; time period: pre-intervention vs. post-intervention). We then applied a Pearson chi-square test to compare the distribution of referrals across periods. When cell counts were < 5, Fisher's exact test was used instead.

All analyses were two-sided, and statistical significance was defined as $p < 0.05$.

Ethics

This study was approved by the Institutional Ethics and Research Committee (IREC) at Moi Teaching and Referral Hospital (MTRH) with reference number IREC/2021/216 and approval number 0004060.

Table 1 Patient clinical characteristics of newly diagnosed children with cancer from Bungoma County ($n = 30$)

Patient characteristics	*N* = 30
Sex	
Male	18 (60%)
Female	12 (40%)
Age at diagnosis	
Below 5 years	14 (47%)
5–10 years	9 (30%)
> 10 years	7 (23%)
Diagnosis	
Nephroblastoma	6 (20%)
Acute lymphoblastic leukemia	6 (20%)
Burkitt lymphoma	3 (10%)
Brain tumor	3 (10%)
Rhabdomyosarcoma	3 (10%)
Nasopharyngeal carcinoma	2 (7%)
Retinoblastoma	2 (7%)
Yolk sac tumor	2 (7%)
Acute myeloid leukemia	1 (3%)
Hodgkin lymphoma	1 (3%)
Neuroblastoma	1 (3%)
Stage for solid cancers	
Low stage	2 (7%)
High stage	17 (57%)
Unknown	4 (14%)
Hematological cancer	7 (23%)
Outcome	
Alive	22 (74%)
Dead	8 (26%)

Results

Characteristics of newly referred children with cancer

In total, 30 children were referred from Bungoma County during the two years following the campaign's start, from January 2023 to December 2024. Of all 30 newly referred children, the parents consented to participate in the parental interview, indicating a mean of 15 new patients per year. The patient characteristics are displayed in Table 1. In total, 12 (40%) were females. The median age was 5.5 years (0–10). Cancers included hematological cancers (7, 23%),solid cancers (20, 67%), and brain tumors (3, 10%). High-stage cancer was reported in 17 out of 23 (74%) solid-type cancer cases and was unknown in 4 (14%). This distribution is comparable to the population of children with cancer presenting at MTRH [34]. Eight children (27%) died during this follow-up period. All these eight children (100%) died within 42 days after diagnosis and are therefore early deaths. Table 2 displays the socio-demographic characteristics of the parents of the 30 newly diagnosed children with cancer. The majority were from the Luyha tribe and Christians by religion. In 11 (37%) families, there was a stable income; in 63%, the main income provider was the father. The median income was 20,000 Kenyan shillings (approximately 145 euros) per month. Parents had an average of 3.6 children, ranging from 1 to 9 children per family. No families reported having any deceased children. These socio-demographics align with the county data for Bungoma [20]. Regarding SHIF, 18 (60%) reported having SHIF before arriving at MTRH. This is higher compared to historical data on health insurance on arrival for children with cancer [36]. In total, 28 (93%) families reported losing income when having to come to MTRH, and 24 (80%) reported losing profits from farming when coming to MTRH. The family often had to travel a considerable distance to reach MTRH, with a mean distance of 106 (*24 SD*) kilometers. Families reported that transportation was difficult (90%), time-consuming (90%), and expensive (97%).

Delays of newly referred children with cancer

Median (range) patient delay was 30 days (0–364), median (range) physician delay was 104 days (4–440), median (range) diagnosis delay was 113 days (30–472), median (range) treatment delay was 6 days (−11–71), median (range) health system delay was 114 days (8–436) and median (range) total delay was 146 days (35–468). (Fig. 1) The negative value minimum range for treatment delay was related to the initiation of nephroblastoma treatment on the basis of a presumptive diagnosis, made based on clinical findings and available ultrasound scanning, in two patients while awaiting a CT scan. In

Table 2 Socio demographic characteristics of newly diagnosed children with cancer from Bungoma County ($n=30$)

Main caregiver in hospital	N = 30
Mother	17 (56%)
Other	8 (27%)
Father	5 (17%)
Parental information when caregiver was a parent	N = 22
Highest level of caregiving parent	
Secondary school/high school	12 (54%)
Primary school	7 (32%)
Diploma/university	3 (14%)
No education	0 (0%)
Tribe of caregiving parent	
Luyha	15 (68%)
Saboti	2 (9%)
Bukusu	2 (9%)
Teso	1 (4%)
Other	2 (9%)
Religion of caregiving parent	
Christian	21 (96%)
Muslim	1 (4%)
No religion/Other religion	0 (0%)
Occupation caregiving parent	
Farmer	8 (36%)
Business	7 (32%)
No occupation	4 (18%)
Teacher	2 (9%)
Househelp	1 (4%)
Transportation	N = X (%)
Distance from MTRH (Mean (*SD*))	106 (*24*)
Distance from MTRH classified	
0–15 km	0 (0%)
15–30 km	0 (0%)
30–50 km	1 (3%)
50–100 km	11 (37%)
> 100 km	18 (60%)
Type of transport used	
Public transport	17 (56%)
Hospital Ambulance	10 (33%)
Walking	2 (7%)
Private car	2 (7%)
Taxi	0 (0%)
Time to travel to MTRH	
< 1 h	0 (0%)
1–3 h	24 (80%)
> 3 h	6 (20%)

Kenya, it is standard practice to start presumptive treatment based on imaging for nephroblastoma. The rather long maximum range value for diagnosis delay is caused by long delays in three patients with a yolk sac tumor, a nephroblastoma, and a Burkitt lymphoma. The largest contributor to the total delay is diagnosis delay, mainly due to long physician delays.

Patient delay

Regarding patient delays, we explored several factors that could contribute to such delays: actions taken upon the onset of symptoms, parental beliefs about childhood cancer, TCAM usage, and transportation challenges. Symptoms reported by parents at onset varied and included swelling at the affected site, loss of appetite, fevers, headaches, general body weakness, pain, and bleeding. As an initial response to these symptoms, 29 (97%) reported visiting a health facility, 19 (63%) prayed, 15 (50%) sought advice from relatives, 10 (33%) consulted an herbalist, and 1 (3%) chose to watch and wait. Reasons for TCAM usage prior to diagnosis are shown in Table 3. The most common forms of TCAM utilized were: prayer (30, 100%), visits to an herbalist (12, 40%), consultations with a traditional healer (4, 14%), special dietary intake (4, 14%), and witchcraft (1, 4%). Recommendations for TCAM usage came from relatives (60%), friends (53%), grandparents (50%), religious communities (43%), spouses (40%), and village communities (23%). Additionally, relatives (17%), friends (14%), village communities (7%), spouses (3%), religious communities (3%), and grandparents (3%) advised against seeking conventional care. In 20 (67%) cases, families were encouraged to go to MTRH, while in 8 (27%) cases, they were discouraged from going to MTRH. Two (7%) reported that some people in their environment encouraged them, while others discouraged them from going to MTRH. In terms of beliefs and fears regarding surgical management of their child's condition, parents reported the following perceptions: frightening (20, 67%), necessary (20, 67%), helpful (19, 63%), spreads the cancer (9, 30%), and causes death (4, 13%). Regarding the awareness program posters and radio campaign, only 7 (23%) families reported seeing a poster about childhood cancer symptoms. Of these 7 cases, only one was alerted to the symptoms and urged to seek care. For the radio campaign, 13 (43%) families reported hearing a message about childhood cancer symptoms. In one of these cases, this alerted them to the symptoms, and in two cases, it motivated them to seek care.

Physician and diagnosis delay

The first point of contact with a conventional healthcare provider was usually a dispensary (12, 40%). Other first-contact healthcare facilities included health centers (6, 20%), private hospitals (8, 27%), sub-county hospitals (2, 7%), county hospitals (1, 3%), and a mission hospital (1, 3%). Most commonly, the child was seen by a nurse (13, 43%) or a clinical officer (8, 27%). Upon this first contact, 22 (73%) children were first managed for a disease other than the later diagnosed cancer. These other conditions ranged from malaria to pneumonia, typhoid, pain control, or other infectious diseases. The median duration of management for this other condition was 13.5 days (range

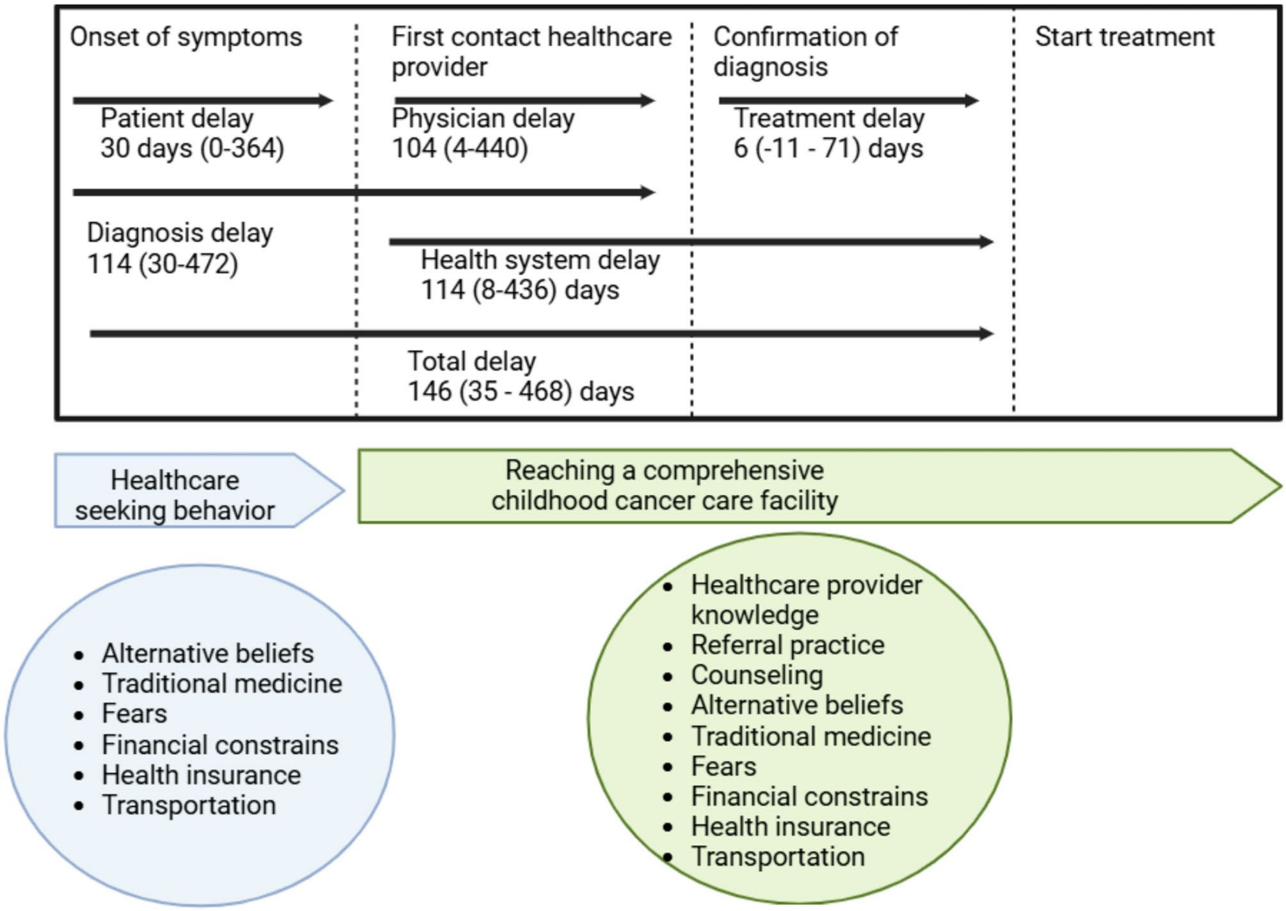

Fig. 1 Overview of different types of delays and causes

Table 3 Reasons for traditional alternative and complimentary usage prior to diagnosis

Reasons for TCAM	
Hope for improvement	28 (93%)
Hope for cure	28 (93%)
Helpful	26 (87%)
Certainty of cure	26 (87%)
Easily accesible	20 (67%)
Cheap	18 (60%)
Recommended by others	16 (53%)
At a short distance available	14 (47%)
Other patients look healthy after taking it	11 (37%)
Fear of surgery in hospital	6 (20%)
No discomfort	4 (13%)
Child will not be detained in the hospital	4 (13%)
No side-effects	4 (13%)
No health insurance	3 (10%)
Conventional treatment has not certainty of cure	1 (4%)
Child can stay in the family	1 (4%)

1–60 days). In 11 (37%) of children, the healthcare provider referred them to another doctor. In 2 (7%), this was directly to MTRH. During this referral, in 2 of 11 referred children, the healthcare provider mentioned cancer as a potential diagnosis. In one of these two cases, the healthcare provider mentioned the curability of cancer, the affordability of cancer treatment, and the importance of conventional medicine to cure it. In 10 (33%) children, the healthcare worker advised the family to register for SHIF. Reasons for delay in going to MTRH after referral are displayed in Table 4. The majority of the parents had heard of cancer in children (20, 67%) and did not think childhood cancer was curable (25, 83%) or affordable 27 (90%). Upon arrival at MTRH, most children were seen at the Sick Child Clinic (27, 90%). In total, 6 (20%) children were already diagnosed in another facility upon presentation. The newly diagnosed children at MTRH were commonly seen by a clinical officer (16, 53%), doctor (4, 14%), or other healthcare provider (1, 3%), and 9 (30%) parents did not know which type of healthcare provider attended to them. All 30 (100%) children were admitted for investigations on childhood cancer at MTRH after consultation.

Comparison of referrals before and after the start of the implementation of the awareness campaign

During the pre-intervention period (2014–2022), a total of 1,959 children with cancer were referred to MTRH, of whom 153 (7.8%) originated from Bungoma County. In the post-intervention period (2023–2024), 552 children were referred to MTRH, of whom 30 (5.4%) were from Bungoma County (Fig. 2). Comparison of proportions showed that the difference between the two periods did not reach statistical significance (Chi-square test, $p = 0.071$; Fisher's exact test, $p = 0.063$).

Discussion

This study evaluated newly diagnosed children with cancer from Bungoma County following the implementation of an awareness campaign. Over a two-year period, 30 children were referred from Bungoma, far below the expected 140 annual cases [25]. No significant increase in referrals was observed compared to historical data. Lengthy delays in accessing care at MTRH were attributed to multiple factors, including the financial burden of travel and hospital services, as well as the complexity of referral systems between primary and tertiary healthcare. Most parents lived over 100 km from MTRH, relied on public transport, and faced financial challenges such

Table 4 Reasons for delayed presentation at Moi teaching and referral hospital after referral

Referral Pathway	N = X (%)
Difficulties in first visit healthcare provider	
Hospital costs	22 (73%)
Travel costs	23 (77%)
Loss of daily wages	19 (63%)
Distance from clinic	17 (57%)
Fear of surgery	16 (53%)
Fear of cancer treatment	15 (50%)
Hospital procedure to clear the bill	17 (57%)
Not satisfied with care in the past	11 (37%)
Detention of child in hospital	11 (37%)
Poor transport facilities	11 (37%)
Disease of my child may not be curable	10 (33%)
No NHIF	11 (37%)
Fear of side-effects cancer treatment	8 (27%)
Reputation of long delays in public hospital	7 (23%)
Reputation of corruption in public hospital	6 (20%)
Going to work	5 (17%)
Time clinic appointment is inconvenient	4 (14%)
Nobody to look after children at home	4 (14%)
Child appears ill	3 (10%)
Too busy	2 (7%)
Nobody to look after the land	1 (3%)
Do not see benefit of hopsital visit	0 (0%)

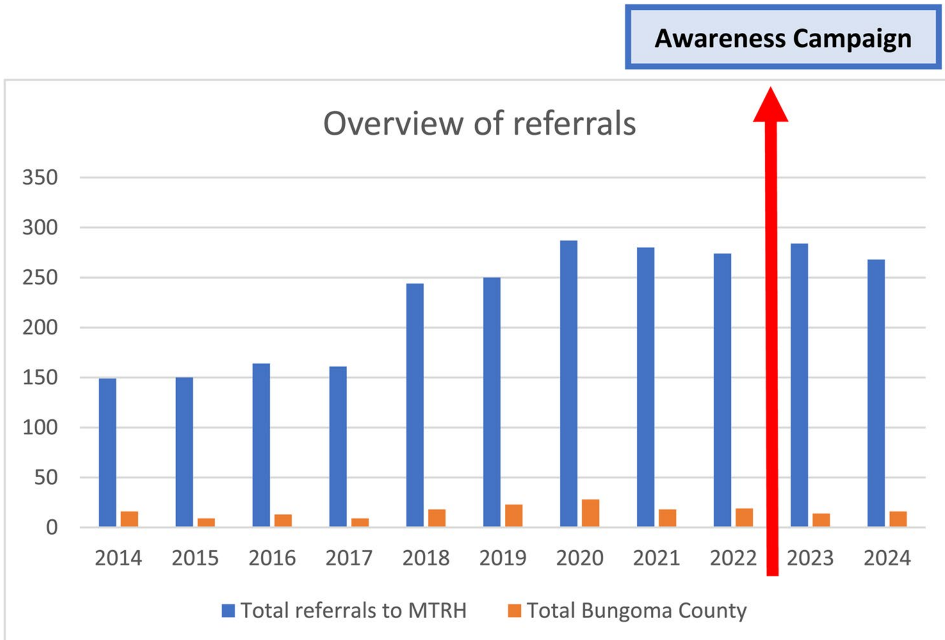

Fig. 2 Overview of annual referrals at Moi Teaching and Referral Hospital and proportion of referrals from Bungoma County

as travel costs, hospital fees, and lost wages. Delays were further influenced by parental engagement with TCAM, often grounded in cultural or spiritual beliefs, as well as concerns about conventional cancer treatment and the comparatively greater accessibility and affordability of traditional care options. These findings highlight the complexity of accessing childhood cancer care and the continued need for targeted actions to ensure timely diagnosis and treatment.

This study found that the awareness campaign did not increase the number of referrals in the two years following the implementation of the awareness program. This shows that the majority of the estimated 140 children from Bungoma County with cancer annually do not manage to reach a comprehensive childhood cancer care facility. Other outcomes, such as increased knowledge amongst healthcare providers after the training, are reported in another publication [37]. Finding adequate measures to report the impact of awareness programs is challenging and often limited to the observed increase in (early) referrals, the knowledge of healthcare providers, and the feasibility of implementing the intervention [38]. Further qualitative research investigating the barriers and facilitators to adequate referrals could enhance the design and implementation of future awareness campaigns. Moreover, longer follow-up monitoring of the program's impact is advisable.

Findings from parental interviews suggest that various factors—including financial barriers, culturally influenced health-seeking behaviors, use of TCAM, and challenges in the referral process—may contribute to delayed or missed diagnoses in children with cancer despite the awareness campaign. However, other studies that examined the impact of awareness and early detection programs on referral rates for childhood cancer report increased referral rates [38, 39]. Interventions in these studies differed from ours, as some focused only on retinoblastoma campaigns [38, 40]. The impact of the interventions in these studies was measured over longer periods of time and therefore also includes a natural trend of increase that is a consequence of the evolution of health literacy, healthcare seeking, and universal health coverage after the intervention [38]. Additionally, the lower-than-expected numbers of referrals from Bungoma County after the campaign could be attributed to several confounding factors—such as healthcare worker strikes, shortages of medical supplies at the referral hospital, and patients seeking treatment at other facilities.

This study revealed that children who were newly diagnosed after the implementation of the awareness program still arrived late. The prolonged total delays identified in this study led to a majority of patients presenting with advanced stages, resulting in lower survival chances. The parental interviews highlight the financial and cultural factors that influence conventional healthcare-seeking behavior. Studies conducted in LMICs have found that TCAM is commonly used in the context of childhood cancer, reflecting its important role in local health beliefs and care practices [8–10, 28, 32]. Given that TCAM is deeply integrated into community healthcare systems, it is essential to recognize its role and explore opportunities for respectful collaboration, as some complementary practices may enhance or support conventional medical care and could foster mutual trust in both types of medicine.

Physician delay was the main contributor to total delays in this study. This could be linked to lower self-reported patient delay. Interestingly, this physician delay persisted after the awareness campaign's training for primary healthcare workers in Bungoma County. This could be related to referral policies that require patients to pass through level 4 and 5 facilities before reaching level 6 hospitals, such as MTRH, which can cause delays. This is evidenced by the parental interviews, which show an average of four clinic visits before arrival at MTRH. Engagement and training with level 4 and 5 facilities might address this. Additionally, parents may be reluctant to seek a referral due to the expected costs, lack of health insurance, and low trust in public facilities. Referral practices and health insurance have been indicated to influence delays in access to childhood cancer care [4, 28, 32, 34]. It is therefore important for healthcare workers not only to recognize childhood cancer but also to promptly refer to a comprehensive childhood cancer care facility [31]. Finally, the integration of TCAM and the varied health beliefs among healthcare providers in Bungoma County may shape referral behaviors, highlighting the need for continued dialogue and collaboration, especially in the context of ongoing training [41]. Physician delays are one of the components that delay access to care, as addressed in several studies included in the systematic review of Cotache-Condor et al. [28]

Strengths and limitations

This study is one of the few that investigates the impact of an awareness program through referral monitoring and thoroughly analyzes the patient journey concerning delays. Due to the rarity of the disease, the sample size of this study is low. The relatively short follow-up period after the intervention did not allow for assessing long-term trends or delayed effects of the intervention. However, the main effect of the intervention was expected within the first 24 months after the start of the training sessions. A longer follow-up is recommended to further explore the potential long-term or delayed effects of the intervention.

Conclusion

This awareness program in Bungoma County highlights that improving early detection of childhood cancer requires a multifaceted and sustained approach. Efforts must extend beyond one-time interventions, encompassing consistent community engagement, health system strengthening, and sustained long-term investment in awareness. In addition to education and training, national advocacy for expanded health insurance coverage for childhood cancer is essential to address financial barriers that often delay or prevent families from seeking timely care. Moreover, given the significant role of TCAM within community health systems, it is vital to promote respectful collaboration between conventional and traditional healthcare providers. Such partnerships can help bridge gaps in understanding, enhance trust, and ultimately support better outcomes for children with cancer.

Abbreviations

LMIC	Low and middle income country
HCP	Healthcare provider
GICC	Global Initiative for Childhood Cancer

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

LK drafted the manuscript, conducted data analysis, was involved in data collection and entry.LA reviewed the manuscriptSK conducted data collection and entryTV reviewed the manuscriptSV assisted in drafting the manuscript and reviewed the manuscriptGK reviewed the manuscript and provided supervision on the programFN reviewed the manuscript and provided supervision on the program.

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Data availability

The data generated by this study will be made available upon reasonable request.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the local guidelines and, as such, was approved by the Institutional Ethics and Research Committee (IREC) at MTRH (Moi Teaching and Referral Hospital) with reference number IREC/2021/216 and approval number 0004060.
All patients who participated in this study were enrolled only after an informed consent procedure in Kiswahili.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Conflict of interest

The authors declare no conflict of interest.

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