

Social Reintegration and Stigma Among Childhood Cancer Survivors in West Kenya

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Purpose: The population of childhood cancer survivors in low- and middle-income countries is set to increase due to diagnosis and treatment advancements. However, cancer is still associated with stigma that may hinder societal re-entry. This study explores the social reintegration and stigmatization of Kenyan childhood cancer survivors to develop targeted interventions for follow-up care.

Methods: Adult survivors of childhood cancers who completed treatment at the largest referral hospital in Western Kenya were interviewed using semi-structured questionnaires between 2021 and 2022. Stigma was assessed using the Social Impact Scale.

Results: Twenty-six survivors (median age 20 years) were interviewed, with 16 (62%) being males. All survivors missed classes during treatment, and 16 (62%) had to repeat school grades after treatment completion. Many (13; 50%) reported negative feelings about the situation at school. Six (23%) were excluded from school activities and four were bullied (15%). Most 25 (96%) could not openly speak about cancer to all community members. Reasons for lacking social support, avoidance, and discrimination were cancer is a curse, contagious, or inheritable. Nine (35%) felt that their marital prospects were negatively affected by their cancer history. Stigma was higher for survivors who received a negative response after cancer disclosure ($p = 0.001$) and survivors with negative perspectives on their marital prospects ($p = 0.002$). Survivors recommended community and school education, peer support groups, and counseling.

Conclusion: Childhood cancer survivors in Kenya face difficulties with social reintegration and stigmatization. Outreach campaigns focusing on education at schools and communities should be implemented. Counseling and support groups may facilitate re-entry into society.

Keywords: childhood cancer, survivorship, social reintegration, stigma, Kenya

Introduction

Worldwide, the population of childhood cancer survivors (CCS) is increasing due to advancements in diagnosis and treatment.¹ The World Health Organization's (WHO) Global Initiative to improve the survival of six common and curable childhood cancers to 60% by 2030 is likely to further increase the population of childhood CCS in low- and middle-income countries (LMIC).² This has led to enhanced interest in the research of this population across the globe.³

Despite this progress, cancer is still associated with a great amount of stigma.⁴ Studies have reported that cancer is often regarded as a death sentence by both the patients and the

community.⁵ This stigma can negatively impact CCS' social reintegration and affect employment, relationships, and social activities throughout their lives.⁵⁻⁸

Studies from LMICs reporting on the socioeconomic and psychological impact of childhood cancers are scanty. In Kenya and the entire sub-Saharan Africa, information on the stigma and social reintegration of CCS is lacking.⁹ A previous Kenyan study found that during cancer treatment, some children and their families were socially isolated by their communities. The families concerned were not spoken to, disregarded, shut out from social activities, and severed from the resources of the farming land.¹⁰ This clearly illustrates that much more attention should be directed toward ending stigmatization and discrimination against CCS.

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The study aimed to explore the survivors' experiences of social reintegration and stigma at the school, workplace, and community levels. Marital prospects were also examined. In addition, recommendations were sought from the survivors on how children with cancer can best be reintegrated into their communities.

Methods

Setting

The study was conducted at Moi Teaching and Referral Hospital (MTRH). MTRH is a tertiary care referral hospital located in Western Kenya whose service area covers a population of approximately 24 million.¹¹ The total bed capacity is approximately 1000, of which 35 are for the pediatric oncology department. Treatment modalities offered in the department include surgery, chemotherapy, and radiotherapy. Payment of services is through out-of-pocket payments or by insurance.¹² The National Health Insurance Fund is a public scheme where families contribute a minimum of 5 USD per month.¹²

Study design

This cross-sectional study explored social reintegration and stigma among Kenyan CCS. The inclusion criteria were CCS (age ≥ 18 years) diagnosed with cancer between January 1, 2010, and December 31, 2019, with at least 1-year event-free survival after treatment completion. This was because a significant percentage would relapse if we included survivors immediately after treatment.

Study questionnaire

The questionnaire was prepared by Dutch, American, and Kenyan doctors who made sure that every statement was appropriate and clear. The questionnaire was first designed in English and thereafter translated to Kiswahili. The translation was done following a standard forwards-backwards process.

The questionnaire covered six major themes: school attendance, employment, social support after cancer disclosure, marital prospects, stigma, and recommendations on social reintegration. The questionnaire consisted of closed-ended questions requiring participants to evaluate 2- to 5-point scales. There were several open-ended questions as well. Stigmatization was measured with the validated Social Impact Scale (SIS) of Fife and Wright.¹³ This Social Impact Scale has extensively been employed to investigate stigma among patients with cancer, Human Immunodeficiency Virus (HIV)/AIDS, hepatitis C, and COVID-19.^{14–18} Three of its subscales were used in our study: social rejection (nine items), internalized shame (five items), and social isolation (seven items). The fourth financial stigma subscale was not included since the survivors did not own any capital during childhood. Responses to the statements were given on a Likert scale with scores ranging from 1 point (strongly disagree) to 4 points (strongly agree). Total SIS scores were as follows: social rejection (9–36 points), internalized shame (5–20 points), social isolation (7–28 points), and sum SIS (21–84). The higher the score, the worse the stigmatization.

The coefficient alphas for our sub-scales were 0.86 for social rejection (excellent), 0.40 for internalized shame (poor), and 0.89 for social isolation (excellent).¹⁹

Participant recruitment

From January 2010 until December 2019, 1472 children were newly diagnosed with cancer at MTRH. Based on findings from a prior study, an estimated 450 children had completed treatment.²⁰ Approximately 100 of these children met the inclusion criteria. Valid contact details were available for 52 survivors. Convenience sampling was used, and recruitment took place for a year. Survivors were recruited in the outpatient clinic or were given study details during a phone call to encourage them to come to the hospital for a follow-up evaluation. No compensation was offered for their participation in the study.

Data collection

The survivors were interviewed from November 2021 to October 2022. Survivors were consented and interviewed at the follow-up clinic. If a survivor was unable to attend the follow-up clinic they would be interviewed at their homes. Each interview took approximately 60–90 minutes.

The interviews were done in English or Kiswahili, depending on the survivor's preference. The interviews were conducted in person by three researchers (S.M., J.L., and N.M.). We conducted a pilot study that included five CCSs to test for content, clarity, and cultural appropriateness. Afterward, a few questions were clarified or rewritten. Some questions were also added. Data on the baseline characteristics of the survivors (diagnosis, date of diagnosis, date of starting treatment, date of completing treatment, date of last follow-up visits, and their health insurance status) was extracted from the medical records. Participants were interviewed on late effects, presence, performance limitations of daily life activities, school attendance, response upon cancer disclosure, perspective on marital prospects, bullying at school, and time since treatment completion.

Ethical considerations

The study protocol was approved by the Institutional Research and Ethics Committee (FAN: 0004007). Informed consent was sought, with participants signing a consent form. Participants were assured of anonymity, confidentiality, and privacy. They were also made aware of their right to withdraw from the study at any time.

Data analysis

Data was transferred from the questionnaires to a secure data capture system (Castor Electronic Data Capture). The data were then extracted and analyzed using SPSS. Measures of central tendency (mean, median, and mode) and frequencies were obtained. Differences between social reintegration or stigma and the survivor's baseline characteristics (age at diagnosis, sex, type of cancer, age at interview, self-reported late effects presence, performance limitations of daily life activities, school attendance, response upon cancer disclosure, perspective on marital prospects, bullying at school, and time since treatment completion) were compared using the Chi-square test or Fisher's exact test. Regression analysis was done to determine the association between social rejection, internalized shame, social isolation, and the survivor's

baseline characteristics. A two-sided p -value <0.05 was considered statistically significant.

Results

Survivor characteristics

In total, 26 survivors (50%) were interviewed, at the follow-up clinic (14; 54%), or at a home visit (12; 46%). Table 1 shows the sociodemographic and clinical characteristics of the survivors. More males (16; 62%) than females (10; 38%) were enrolled in this study. The median age at diagnosis and during the interview was 12.5 years (interquartile range [IQR] 10.8–14.2) and 20 years (IQR 18–22.5), respectively. The majority were survivors of hematological cancers (19; 73%), and chemotherapy (25; 96%) was the most used treatment modality. Many survivors (19; 73%) had experienced a late effect, such as pain and fatigue. Survivors 11 (42%) had limitations in daily life activities: personal care, physical work, social activities, daily chores, school, and jobs. Few survivors (4; 15%) had other health issues that required medical consultation: HIV, abdominal pain, lumbar lordosis, heart problems, and bleeding conditions. Most survivors (20; 77%) were living with their parents.

Education

The majority of the survivors (24; 92%) attended school during treatment. Only two survivors (8%) failed to attend any classes during treatment. Sixteen (62%) missed so many classes that they had to repeat school grades after treatment completion. One survivor (4%) missed so many classes that they had to leave school. At the time of the interview, 18 (69%) survivors were still pursuing education. The highest level of education attained at that time was primary school (1; 4%), high school (17; 65%), and tertiary education (8; 31%). In total, three (17%) of these survivors were limited in their performance at school due to their physical condition.

Some survivors (7; 27%) did not speak to anyone about their illness in the school, whereas other survivors (19; 73%) spoke to teachers (12; 46%), pupils (12; 46%), and principals (8; 31%). Survivors (9; 35%) reported that their teacher informed the class about their cancer history in a sensitive manner that helped them be accepted by their classmates.

On returning to school after treatment completion, survivors reported difficulties such as discrimination due to hair loss, amputation, and change in skin and hair color; difficulties in coping due to missed classes during treatment; and school-mates' belief that cancer is contagious or that they had HIV.

When asked about how they felt about the situation at school, 13 survivors (50%) reported negative feelings: worry (7; 54%), fear (5; 38%), loneliness (4; 31%), sadness (4; 31%), hopelessness (2; 15%), feeling depressed (2; 15%), anger (2; 15%), and shame (1; 8%). Two (15%) survivors reported having trouble sleeping. Survivors were excluded from school activities (6; 23%), had trouble getting along with others (4; 15%), and were bullied (4; 15%). Three (12%) reported that some people were against them returning to school because they believed cancer survivors were contagious, bewitched, would be bullied, or feared by fellow students.

TABLE 1. SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF CHILDHOOD CANCER SURVIVORS (N = 26)

Characteristics	N (%)
Sex	
Male	16 (62%)
Female	10 (38%)
Age at interview (years)	
18–20	17 (65%)
21–23	5 (19%)
24–26	4 (15%)
Median age at interview	20 (IQR 18–22.5)
Age at diagnosis (years)	
6–9	4 (15%)
10–13	13 (50%)
14–16	9 (35%)
Median age at diagnosis	12.5 (IQR 10.8–14.2)
Diagnosis	
Non-Hodgkin lymphoma	8 (31%)
Hodgkin lymphoma	6 (23%)
Acute lymphoblastic leukemia	5 (19.2%)
Germ cell tumor	2 (7.7%)
Osteosarcoma	3 (11.5%)
Kaposi sarcoma	1 (3.8%)
Unknown	1 (3.8%)
Treatment	
Chemotherapy	19 (73%)
Chemotherapy + surgery	5 (19%)
Chemotherapy + surgery + radiotherapy	1 (4%)
Unknown	1 (4%)
Follow-up	
Median time since treatment completion	7.2 years (IQR 5.1–9.9)
Median follow-up duration	3.3 years (IQR 0.7–5.8)
Lost to follow-up before interview ^a	15 (58%)
Self-reported late effects	19 (73%)
Performance limitations of daily activities	11 (42%)
Health-insurance after treatment	
Yes	18 (69%)
No	8 (31%)
Living with parents	
Yes	20 (77%)
No	6 (23%)
Marital status	
Single	24 (92%)
Married	2 (8%)
Parental status	
No children	23 (88%)
Children	3 (12%)
School attendance at the time of the interview	
Yes	18 (65%)
No	8 (35%)
Highest education level at the time of interview	
Primary school	1 (4%)
High school	17 (65%)
Tertiary education	8 (31%)
Employment	
Yes	5 (19%)
No	21 (81%)

IQR, interquartile range.

^aSurvivor was “lost to follow-up before the interview” if the last hospital visit was ≥ 24 months before the interview.

Employment

Survivors (10; 38%) reported that they were currently restricted in performing physical work due to their physical condition. Among the eight survivors (31%) who did not attend school at the time of the interview, five (63%) were employed. Three (37%) were unemployed. None of the employed survivors had been discriminated against by their colleagues or had their job security negatively affected due to their cancer history. One survivor reported that work had become more tedious after treatment completion. All three unemployed survivors had late effects and performance limitations in their day-to-day activities. One (4%) survivor had been rejected for jobs due to the cancer history.

Social support after cancer disclosure

Table 2 shows that many survivors ($n = 25$, 96%) could not speak openly about their cancer to all members of their community. Three survivors (12%) had not been open to anyone about their cancer history. Survivors were most often able to speak to their mothers (19; 73%), and fathers (13; 50%). Six survivors (26%) expressed that they had received a negative response after disclosing their cancer. They were abandoned by a parent, disappointed, or avoided by members of their community.

Reasons for lacking social support, avoidance, and discrimination included people thinking that cancer was a curse, contagious, or inheritable. One survivor was avoided because people thought that his father was a cultist and hence was sacrificing him. Another survivor explained that his cousins were not allowed to eat, sleep, or even play with him. Survivors were also excluded from community activities such as farming. Grandparents blamed a survivor's mother because it was believed that cancer was inherited from her side of the family.

Marital prospects

Some survivors felt they were less likely to get married because others thought childhood cancer was heritable (6; 23%) or that their family was cursed (4; 15%). Some thought their marital prospects were reduced because of fear that they were incapable of having children in the future (9; 35%). Few felt that their family members have less chance of getting married because childhood cancer is heritable (6; 23%) and that their family is cursed (6; 23%). Two survivors thought that engaging in a relationship may be difficult due to stereotyping, and one thought that separation from a prospective spouse would be inevitable due to community gossip. Another survivor believed cancer treatment can cause

impotence. One married survivor said it was challenging to get a spouse because ladies believed he had a short lifespan.

Stigma

Table 3 presents the stigmatization of CCS according to the Social Impact Scale.

Survivors felt that people acted like they were less competent (6; 23%) and avoided them because of the previous illness (6; 23%). Several felt rejected by family members (10; 38%) and friends (9; 34%) because of their cancer. Some reported that they encountered embarrassing situations because of the previous illness (6; 23%), and others seemed awkward when around them (5; 19%). Social rejection was higher for survivors who had received a negative reaction upon cancer disclosure ($p = 0.001$) and survivors who had negative perspectives on marital prospects ($p = 0.008$).

Many (11; 42%) felt that they could not be open with others about the previous illness. Nine (35%) feared that someone was disclosing their previous illness without their permission. Five (19%) felt that they were partially to blame for the previous illness. Internalized shame was higher for survivors having received a negative reaction upon cancer disclosure ($p = 0.026$).

Eight (31%) felt different from those who have always been healthy. Many (13; 50%) had a greater need than usual to hear that others cared about them. Seven (27%) felt less competent than they did before they got ill. Eight (31%) felt that changes in their appearance had affected their social relationships. Social isolation was higher for younger survivors (6–9 years) at diagnosis ($p = 0.016$), survivors having been bullied at school ($p = 0.035$), and survivors having negative perspectives on marital prospects ($p = 0.004$).

Sum SIS was 38.9 (standard deviation [SD] 19.4, maximum 70). The sum of means was: social rejection, 14.8 (SD = 8.5), internalized shame, 10.1 (SD = 4.5), and social isolation, 14.0 (SD = 6.5). Sum SIS was higher for survivors who had received a negative response after disclosure ($p = 0.001$) and those who had expressed negative responses towards their marital prospects ($p = 0.002$).

Recommendations about re-integration by survivors

The survivors gave the following recommendations on how children with cancer can best be guided into returning to school or the community.

The survivors recommended that schools provide mental and spiritual support in the form of guidance and counseling for the survivors. Both teachers and parents should motivate survivors. Students should be educated on cancer, its

TABLE 2. RESPONSE OF COMMUNITY MEMBERS UPON CANCER DISCLOSURE ($N = 26$)

Response upon cancer disclosure	Mother	Father	Grand-parents	Relatives	Friends	Neighbors	Religious leaders	Religious community
Able to speak openly about cancer	19 (73%)	13 (50%)	9 (35%)	10 (38%)	16 (62%)	9 (35%)	11 (42%)	9 (35%)
Supportive	25 (96%)	20 (77%)	17 (65%)	19 (73%)	21 (81%)	15 (58%)	17 (65%)	13 (50%)
Disappointing response	1 (4%)	0 (0%)	0 (0%)	2 (8%)	2 (8%)	2 (8%)	0 (0%)	0 (0%)
Abandoned or avoided family	0 (0%)	0 (0%)	2 (8%)	1 (4%)	0 (0%)	2 (8%)	0 (0%)	1 (4%)

TABLE 3. STIGMATIZATION OF CHILDHOOD CANCER SURVIVORS ACCORDING TO SOCIAL IMPACT SCALE (N = 26)

	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
Social rejection				
"My employer/co-workers have discriminated against me." (n = 16)	0 (0%)	0 (0%)	5 (31%)	11 (69%)
"Some people act like I am less competent due to the previous illness"	3 (11%)	3 (11%)	12 (46%)	8 (31%)
"Others treat me with less respect than usual"	1 (4%)	1 (4%)	10 (38%)	14 (54%)
"Others are concerned that cancer is contagious and that they can catch cancer through contact, like a handshake or eating food I prepare"	2 (8%)	3 (11%)	6 (23%)	15 (58%)
"Others avoid me because of the previous illness"	2 (8%)	4 (15%)	7 (27%)	13 (50%)
"Some family members rejected me because of my previous illness"	6 (23%)	4 (15%)	5 (19%)	11 (42%)
"Some friends rejected me because of my previous illness"	4 (15%)	5 (19%)	8 (31%)	9 (35%)
"I encounter embarrassing situations as a result of the previous illness"	3 (11%)	3 (11%)	12 (46%)	8 (31%)
"Others seem awkward and tense when they are around me"	5 (19%)	0 (0%)	11 (42%)	10 (31%)
Mean score (9–36): 14.8 points (SD 8.5)				
Internalized shame				
"Others blame me for the previous illness"	1 (4%)	1 (4%)	11 (42%)	13 (50%)
"I do not feel I can be open with others about the previous illness"	5 (19%)	6 (23%)	9 (34%)	6 (23%)
"I fear that someone is telling others about the previous illness without my permission"	5 (19%)	4 (15%)	14 (54%)	3 (11%)
"I feel the need to keep the previous illness a secret"	3 (11%)	2 (8%)	12 (46%)	9 (35%)
"I feel that I am at least partially to blame for the previous illness"	0 (0%)	5 (19%)	8 (31%)	13 (50%)
Mean score (5–20): 10.1 points (SD 4.5)				
Social isolation				
"I feel different from others who have always been healthy."	2 (8%)	6 (23%)	8 (31%)	10 (38%)
"I have a greater need than usual to hear that others care about me."	5 (19%)	8 (31%)	7 (27%)	6 (23%)
"I feel lonely more often than usual"	1 (4%)	3 (11%)	13 (50%)	9 (35%)
"I feel less worthy in social relationships (friends, family, or romantic relationship)"	1 (4%)	3 (11%)	12 (46%)	10 (38%)
"I feel less competent than I did before I got ill"	3 (11%)	4 (15%)	11 (42%)	8 (31%)
"Due to the illness, I sometimes feel useless"	1 (4%)	1 (4%)	12 (46%)	12 (46%)
"Changes in my appearance have affected my (friends, family, or romantic relationship)"	4 (15%)	4 (15%)	10 (39%)	8 (31%)
Mean score (7–28): 14.0 points (SD 6.4)				

treatment, and its effects. Teachers should encourage sharing experiences and discourage isolation, bullying, and discrimination. It should be emphasized that survivors are not different and deserve the same treatment as others. One survivor, however, recommended that teachers should respect their privacy and not disclose their cancer history.

The survivors recommend that the community allow them to share their experiences and that the community should accept, support, love, and avoid discriminating against them. MTRH staff should visit the communities and raise awareness about cancer not being a death sentence. They also recommended that the church and its leaders should encourage survivor participation in church activities, give spiritual guidance, and pray for the survivors. Survivors stated that counseling would help with self-acceptance and acceptance by society. Lastly, they desired financial support during and after treatment.

Discussion

Education often predicts the likelihood of employment and subsequent income that an individual may get in the future.^{21–23} Studies from high-income countries have shown that cancer survivors miss school during treatment and fall behind in their schoolwork.^{24–26} This was also observed in our study, where most survivors reported missing so many classes that they had to repeat grades. Data on absenteeism among school-going children in Kenya is scant. However, a study in western Kenya reported 77% absenteeism among

primary school-going children over 2 weeks.²⁷ This is still lower than what was reported by CCS in this study, where all had missed classes during their treatment.

Evidence suggests that childhood cancer patients and survivors experience higher levels of bullying compared with the general population.²⁸ In our study, three survivors (12%) were bullied at school because of their cancer history. This was lower than what was reported in other studies from Australia and Korea, where one-third of the interviewees reported having been bullied.^{28,29} This may be due to the small sample size included in this study. Half the survivors in our study had negative feelings about the situation at school. This is almost similar to what was reported in a study from the USA, where 40% of the survivors reported unpleasant experiences with classmates.³⁰ A study on bullying in chronic diseases reported that the more visible a disease is, the higher the likelihood of bullying.³¹ When describing the difficulties encountered upon returning to school, our survivors mentioned that they felt discriminated against due to their appearance (hair loss and change in skin and hair color). This suggests that their appearance made them vulnerable and increased their risk of bullying.

One-third of the survivors did not talk to anyone in school about their illness. Among the minority of children whose teacher informed their classmates about their illness, there was acceptance by the class. This finding is similar to that of a systematic review, which concluded that studies where the children's diagnoses were shared with their classmates reported

lower rates of bullying compared with studies where there was no disclosure.²⁸ This is further affirmed by results from another study, which reported that increased knowledge about cancer by classmates led to less fear and a more positive attitude toward children with cancer.³²

CCS are more likely to be unemployed when compared with their healthy counterparts.^{33,34} The unemployment rate (37%) in our study was slightly higher than that obtained from a study in the Netherlands, which reported an unemployment rate of 34%.³⁵ This unemployment rate may be overestimated considering Kenya's 14% youth unemployment statistics.³⁶ The lack of a comparison with youths of the same age bracket should be considered when discussing unemployment among survivors.

Cancer-related disclosure involves a complex balance of the decision to disclose, the perceived response of the audience, and the methods of disclosure.³⁷ Disclosure may have beneficial psychosocial results, such as improved social relationships and intimacy.^{38,39} In our study, 88% of the survivors had openly talked about their cancer history to someone. An American study reported 71% disclosure to friends, which is slightly higher than the reported 62% disclosure to friends among our survivors.⁴⁰ Only a minority of the responses to disclosure in our study were negative (26%). This indicates that CCS should be encouraged to disclose their cancer history to the community to gain their support.

The word stigma can be used to describe a power situation whereby a person is labeled, stereotyped, separated, and loses status.⁴¹ Stigma towards people with cancer has been shown to create barriers at all stages of cancer care.⁴² Our findings were comparable to what was reported in the cancer arm of the Fife and Wright study conducted in the USA. Our results were higher compared with those of a South Korean study where public stigma was 1.95 (SD = 0.63) and internalized shame was 1.91 (SD = 0.75).⁴³ This may be because the Korean study adopted questions from two scales, hence the perceived meaning and subsequently, how they were answered, changed.

Social isolation, corresponding with public stigma, in this study was higher among younger children (6–9 years) at diagnosis. This agrees with another South Korean study that reported stigma tends to be higher among younger children.⁴⁴ We also found that survivors who had been bullied at school had a higher likelihood of being isolated. Similar to a South Korean study that found a significant association between disclosure and perceived public stigma, our study found a significant association between total SIS scores and disclosure to society.⁴³ Social rejection has been reported to have an impact on the self-worth of survivors.¹³ In our study, higher levels of social rejection and total SIS scores were associated with survivors having negative perspectives on marital prospects. In another study, patients who were vulnerable to stigmatization were likely to avoid close relationships.⁴⁵ It can be postulated that those who felt rejected by society ended up feeling that they were not worthy, hence not feeling positive about their marital prospects.

To address the drivers and effects of stigma, survivors recommended community education, peer support groups, and counseling. In high-income countries such as the USA, community education and engagement have tremendously succeeded in increasing breast cancer screening and fundraising.⁴³

Similarly, in some LMICs, community outreaches have been effective in changing narratives and attitudes toward HIV and mental health.^{46,47} Although peer support groups are beneficial in other chronic diseases such as HIV, diabetes, and hypertension,^{48–50} their utility and impact, among CCS, have not been extensively studied in LMIC. In Malawi, a study on the experiences of caregivers of CCS also specified a need for peer support activities.⁵¹

Our study had several limitations. Our sample size was small, and our findings may, therefore, not be a representation of all the childhood CCS in Kenya. Recall bias may have affected the accuracy of the data as participants were required to remember experiences from the past. Although previous studies using the SIS reported good internal validity, the Cronbach alpha value for the internalized shame SIS subscale was low in our study. This may be due to a lack of homogeneity in the questions (the first three questions focus on shame from others, while the last two questions focus on personal shame).⁵² It may also be due to the short test length (the subscale had only five questions) and the small number of respondents.^{52,53} Participants may also not have answered the questions truthfully because they feared that more stigma would follow.

Despite these limitations, our study adds to the growing body of knowledge globally on cancer-related stigma, especially in an LMIC setting. To counter some of the myths and misconceptions about cancer, outreach campaigns focusing on education at school and the community level should be mounted. Emphasis on counseling cancer patients, survivors, and health care workers is recommended to facilitate their social reintegration. The organization of support groups should also be considered to enable the survivors to deal with stigma and its effects. This combined approach will ultimately reduce stigma and improve the social reintegration of CCS in Kenya.

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Authors' Contributions

S.N.M.: Investigation, analysis, writing—original draft, writing—review and editing, visualization, project administration; J.P.M.L.: Conceptualization, methodology, investigation, writing—review and editing; F.M.N.: Supervision, conceptualization, methodology, writing—review and editing; N.M.: Investigation, writing—review and editing; S.C.L.: Writing—Review and editing; T.A.V.: Supervision, conceptualization, methodology, writing—review and editing; G.J.L.K.: Supervision, conceptualization, methodology, writing—review and editing; S.M.: Supervision, conceptualization, methodology, writing—review and editing.

Author Disclosure Statement

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