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Adolescents' perceptions and lived experiences of cancer patient-hood: a qualitative study

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Abstract

Background Adolescents' perceptions and lived experiences regarding their cancer diagnosis significantly influence their quality of life and treatment adherence. To inform the formulation of tailored interventions, we explored these factors among adolescents receiving care at a sub-Saharan African health facility in Western Uganda.

Methods We conducted a qualitative study from July 2022 to December 2022 at Mbarara Regional Referral Hospital in western Uganda. In-depth interviews were held with 30 adolescents aged 10–17 years who had been diagnosed with cancer. NVivo 12 software was used to develop a codebook and coding framework to generate themes inductively emerging from the data that aligned with the study objectives. Ethical approval was obtained from the Research and Ethics Committee of Mbarara University of Science and Technology.

Results Participants had a median age of 13.5 years; 19 were male. The diagnoses included leukemia ($n = 13$), lymphoma ($n = 10$), and solid tumors ($n = 7$). Initial perceptions regarding their diagnosis were predominantly negative but improved over time as they received information and improved on treatment. Perceptions were poorer among those who responded poorly to treatment and those who had had extremely negative experiences. Negative experiences included body disfigurement, social challenges, emotional distress, physical pain, and interrupted education. Positive experiences included improvement in symptoms and support from health workers and their families.

Conclusion Adolescents initially exhibit poor perceptions towards their cancer diagnosis, which tend to improve with clinical improvement on treatment and support. Their experiences and perceptions are mixed, highlighting the need for specialized/ tailored education and counselling services to address knowledge gaps obtained from the research findings, and hence improve overall care outcomes among the study population.

Keywords Cancer, Adolescents, Pediatric, Perceptions, Experiences

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Introduction

Globally, approximately 400,000 children are estimated to develop cancer each year [1], with 85% of them living in low- and middle-income countries (LMICs) [2], and approximately 25% living in Africa alone, where health systems are least equipped to handle the disease (WHO, 2022). In Uganda, approximately 3000 children develop cancer annually, with 1,000 (a third) diagnosed at the country's four pediatric cancer centers, and only about 30% surviving [3]. At Mbarara Regional Referral Hospital (MRRH) in western Uganda, approximately 120 children are diagnosed each year, a third of whom are adolescents (unpublished hospital medical records).

Receiving a cancer diagnosis during adolescence is challenging because of the significant physical, cognitive, social, and emotional development that occurs during this period [4]. A cancer diagnosis often results in anxiety, worry, and stress, usually caused by the physical and psychological effects of the disease, the typically life-threatening nature of treatment, and its associated stigma. The resulting health impairment and disfigurement lead to a reduced sense of worth, loss of hope, disability, and pain, which can persist even after the cancer has been cured. A cancer diagnosis is often followed by prolonged periods of hospital-based treatment and frequent travel to the hospital, which affects the adolescent activities, education and recreation [5, 6].

Negative experiences of adolescents suffering from cancer lead to much distress and poor quality of life if not properly addressed [7, 8] and they commonly lack adequate understanding of their illness [7]. This may lead to negative attitudes and perceptions regarding cancer, which can impact on their health-seeking behavior, commitment to care, and general outlook on life, contributing to worsened morbidity and mortality [9]. Positive coping strategies including maintaining a normal routine, seeking support, engaging in the preferred activities with loved ones, staying connected to friends and family, help adolescents with cancer to maintain a close to normal functioning. This underscores the need for an effective support system which includes family, friends, and health workers, peers with similar illness [7, 9]. The internal resilience of the individual adolescent also influences how he/she copes with the diagnosis. The lack of an effective support system is likely to lead to negative coping strategies hence may lead to poor disease outcomes.

The perceptions and experiences regarding cancer diagnosis among adolescents have not been sufficiently studied in our region and most of the LMICs since most of the studies done in this area have focused on the statistical component with less regard for the psycho-social aspect of cancer. This study was designed to explore them to inform the formulation of interventions to support services to adolescents diagnosed with cancer in

our region and improve their care and quality of life. The results from this study may be useful for tailored support to adolescents with cancer both at the clinical and policy level but also for future research about long-term survivorship, social/education integration, and innovative support.

Theoretical framework (socio-ecological model)

Social-Ecological Model as a research framework to understand the perceptions, attitudes and experiences of adolescents with cancer (Fig. 1).

Personal characteristics including age development and individual resilience affects understanding of the disease. Different types of cancer have different profiles of morbidity, and mortality. Familial/ interpersonal factors including socio-economic status, beliefs affect readiness to seek appropriate care. At society or community level, beliefs about the disease and alternative healers will affect individuals' perceptions and experience with disease. At the policy level, the efforts to sensitize the public about cancer plus the quality of care in the cancer departments greatly affects perceptions and experiences of patients.

Methods

Study design

The study was a qualitative phenomenological study to explore the perceptions, attitudes, and experiences of adolescents at MRRH Pediatric Cancer Unit (PCU) about their cancer diagnosis.

Study setting

The study was conducted at the Pediatric Cancer Unit (PCU) of Mbarara Regional Referral Hospital (MRRH), a public tertiary hospital serving a population of about six million people in south-western Uganda, half of whom are children younger than 18 years, and 15% are aged 10–17 years [10]. The unit is a 20-bed capacity ward and outpatient clinic that admits approximately 120 children newly diagnosed with cancer each year. It is run by two pediatric oncologists, medical officers, residents, nurses, and psychologists. Medical services offered at the Cancer Unit include in-patient and out-patient evaluation for cancer patients, investigations for the initial cancer diagnosis, and those necessary during the course of treatment. Others include chemotherapy, surgery, blood transfusion services, management of treatment side-effects; these come off as free services when availed by the different funders or the government but when there is no funding support, families pay for these services. MRRH is also the teaching hospital of Mbarara University of Science and Technology (MUST). At the time of the study, 154 children were in active care, and of these, 53 (35%) were adolescents aged 10–17 years. Disclosure of diagnosis is usually made in an initial diagnostic talk,

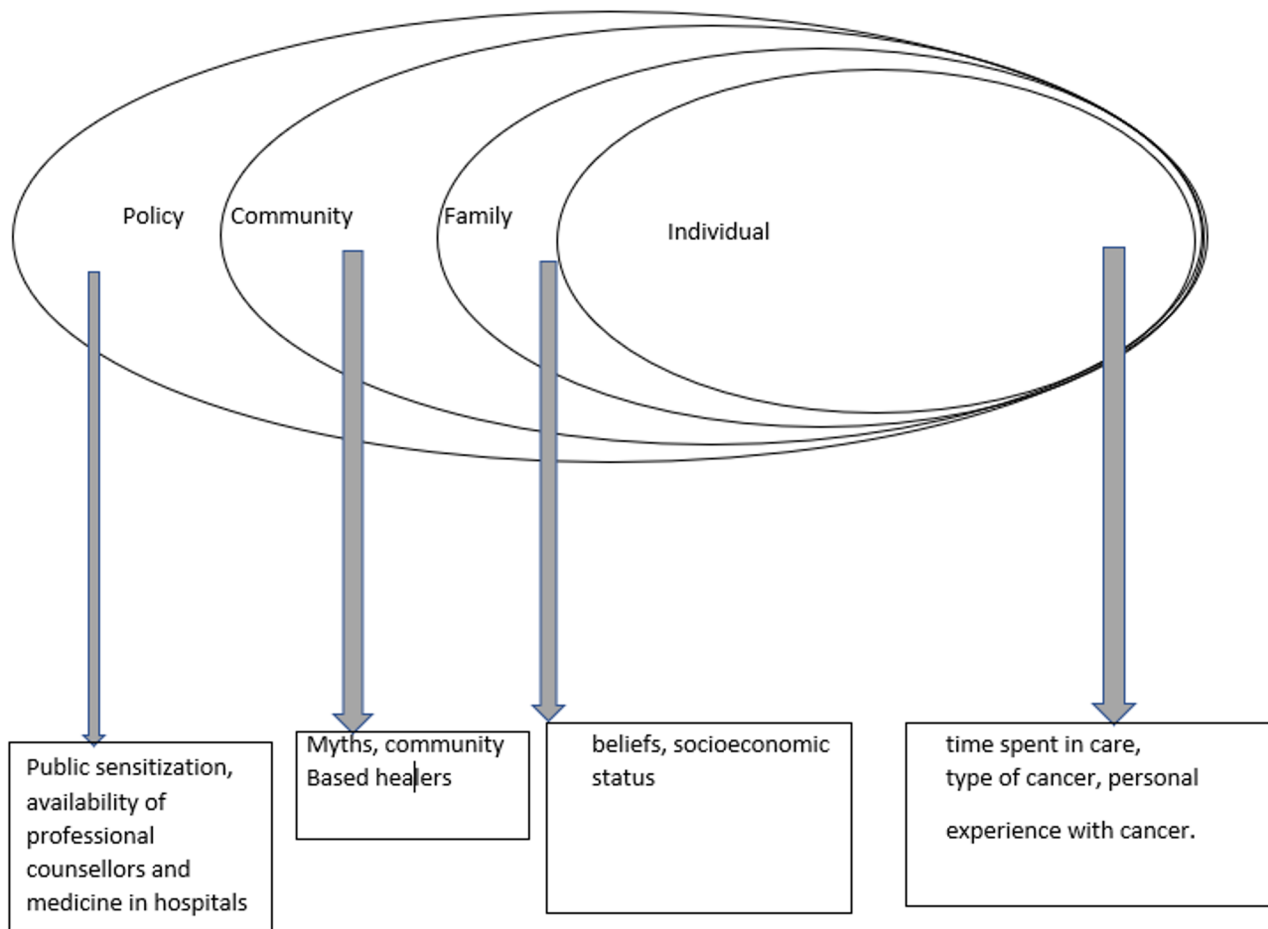


Fig. 1 Social-Ecological Model

to explain the disease, treatment, and expected outcomes to the primary caregivers, which clinically stable adolescent patients may attend.

Study procedure

Between July 2022 and December 2022, we recruited all eligible adolescents aged 10–17 years who had been diagnosed with cancer for at least 2 weeks and were aware of their diagnosis. The range of the period all the participants spent in care was about 2 weeks to 3 years. We determined whether an adolescent was aware of his/her diagnosis by asking him/her, “Do you know the disease with which you have been diagnosed?”. We then enrolled in the study, those who answered in the affirmative. We did not intend to interview adolescents who were not aware of their diagnosis to avoid unintended disclosure. We initially excluded adolescents who were severely ill and unable to participate in a qualitative interview, but were enrolled if they became clinically stable, while the study was still ongoing.

The first author/ principal investigator (MA) and the research assistant then gave a description of the study

purpose and procedure to the eligible participants and their primary caregivers, and those who agreed to participate were guided to sign consent forms. Parents/ caregivers signed consent forms while participants signed assent forms in the language they understood best (English or Runyankore-Rukiga, the local language). The interviews were conducted by the principal investigator and the research assistant during routine clinic visits, home visits and ward admissions and were completed with participants in-person in a private and quiet room to avoid interruptions. Individual semi-structured interviews were conducted via a pre-tested interview guide consisting of open-ended questions and probes. The interviews were conducted in English or Runyankore-Rukiga (the local language) and were audio recorded and backed up by notes written by the research assistant, and lasted between 30 and 60 min. When they permitted their children to participate in the study, caregivers were excluded from the interviews to encourage the participants’ free expression of their ideas. The study received ethical approval from the Research and Ethical

Committee (REC) of Mbarara University of Science and Technology (MUST) (MUST-2022-450).

Data management and analysis

Data analysis and management were performed by the principal researcher with assistance from an experienced qualitative researcher. All the audio data obtained from interviews were transcribed verbatim by the research assistant, and the Runyankore-Rukiga transcripts were translated into English by a skilled translator. The field notes were checked for non-verbal communication cues that could not be picked up by an audio recorder.

Data analysis was conducted throughout the study via a thematic approach. Preliminary data analysis was performed by the research assistant and the principal investigator after 20 interviews; we read through the data several times while identifying interesting phrases and concepts in the data and named them codes. Analysis was repeated after the 25th interview, and no new codes emerged from the interviews. We conducted 5 more interviews to ensure that data saturation had been achieved. We then developed a codebook. Themes were then generated from the related codes to identify broader patterns of data, and consensus was achieved on the final themes after several discussions with the study supervisors. Themes were arranged under corresponding objectives. Codes and themes were organized via NVivo 12 software.

Results

Socio-demographic profile: Thirty-four (34) eligible adolescents were approached for participation. Two adolescents could speak neither English nor Runyankore-Rukiga; two (2) declined to participate, and saturation was reached at the 30th participant. The median age of the 30 participants was 13.5 (IQR 12–16) years, and 19 (63%) were male. Thirteen (43.3%) patients survived leukemia, 10 (33.3%) had lymphoma, and 7 (23.3%) had solid tumors. The majority (17, 56.7%) were from the local Ankole community.

Adolescents' perceptions about cancer

Inadequate knowledge of the causes of cancer

Most participants said that they did not know the cause of cancer, whereas some said that they thought that it was caused by consuming animal-based diets such as meat and milk, and processed foods. Other participants thought that eating contaminated food and the ingesting non-food substances like plastics and small metal particles caused cancer. However, some participants mentioned commonly known risk factors for cancer, such as heredity and unhealthy lifestyles such as smoking and drinking alcohol.

"I used to see other people on ward in the same condition like me and I also knew that it was a disease like any other that is affecting us though I didn't know what had caused it". (14 years, male)

Many participants said that cancer has supernatural causes, including witchcraft from people who disliked them or punishment from God.

"The pastor told us that a witch had put a snake in my body, which lays eggs in my neck (meaning neck lymph nodes), so we know that that is what caused me cancer." (Male, 11 years).

Various modes of treatment are effective for cancer cure

Most of the participants said that the only effective treatment for cancer was the treatment they were receiving at the hospital, including chemotherapy, surgery, and radiotherapy.

"I think the chemotherapy I am receiving is effective because it has helped me feel much better despite its side effects. It is helping me recover, and the severe pain I had stopped". (Male, 11 years).

Some participants said that herbal treatment, consulting spiritual healers, traditional healers and praying to God were also useful because they reduced pain and suffering.

"We went for both prayers and I also took some herbal medicine to help me cure leukemia. I drank about three-5litre jerrycans of herbal medicine for leukemia that we got from a certain traditional doctor. The herbs and prayers made me feel much better. So, the herbs also play a role in the healing process." (15 years F).

Adolescents' reactions to cancer diagnosis

Cancer can be cured successfully

Most of the participants held hopeful attitudes toward a cancer diagnosis and its treatment and felt that cancer is highly curable as long as they observed good adherence to treatment. They believed that treatment was highly effective and were willing to adhere to treatment despite the side effects they encountered. The positive attitudes were further helped by the success treatment stories they had observed or heard about within the Unit and their own marked improvement after initiation of care.

"I am hopeful because I can see an improvement from the time I was diagnosed. The medication I am taking keeps me encouraged, and looking at other patients completely recovered makes me hope that I will also recover." (Female, 10 years).

Fear of impending death

Some participants, especially those who did not improve significantly on treatment or who witnessed the intense suffering and death of fellow patients, said that cancer is generally a complicated disease with poor chances of cure, and some feared that they would die soon.

“Everyone here just keeps dying. Even (mentions name of deceased patient) has just died. I am just tired of taking medication because I know that cancer doesn’t heal.” (With a sad face) (Male, 13 years).

Some adolescents were found to have background attitude that cancer doesn’t heal and there wasting time treating it.

“Everyone here just keeps dying. Even he (mentions name of deceased patient) has just died. I am just tired of taking medication because cancer doesn’t heal.” (He says this with a sad look on his face and talks of postponing intrathecal chemotherapy) (13 years, male).

A ray of hope while in care

In the initial stages of care, most participants noted having held negative perceptions about whether cancer could possibly get cured, but these perceptions continued to improve as they interacted with the health workers and other fellow patients, as well as their promising personal experiences while in care.

“At first, I feared that I wouldn’t get better because I thought that cancer does not cure, but I later gained hope for a cure because when I received treatment and counselling, and I kept improving gradually.” (Female, 15 years).

Emotional and psychological challenges

Many participants described feelings of fear and anxiety upon receiving the bad news about cancer. The emotional and psychological disturbances were more pronounced among older children, those who had thus far shown little improvement on treatment, and those who had witnessed the extreme suffering of their fellow patients.

“They bring children who are very sick, and don’t even spend a week. They die when we are seeing. For example, a child can be playing and looking okay, only for him to die in the evening. That’s so discouraging.” (17 years, male).

Coping strategies of adolescents with cancer

Prayers were particularly reported to be useful for maintaining a positive outlook and hope for a cure. Some

participants acknowledged the role of early diagnosis of cancer, early initiation into care, and compliance with medical treatment.

“The reverend would come for morning and evening mass and I never wanted him to miss because whenever he would come, I would get courage and know that God would heal me” (13 years, female).

Socio-cultural influences on their cancer patient Hood experiences

Social experiences

Most participants felt stigmatized by peers because of their condition and the sickly and disfigured appearance they developed after they started treatment. Some participants said that they were discouraged from making friends with fellow patients because they feared that the friends might later die and leave them alone. Some participants did not receive enough support from their families, especially if the family members thought that the cancer was incurable and that they were wasting time and money on treatment.

“My father is the one who first brought me. When he reached home, he said that he was not coming back here since there’s no cure. He told my mother that they should get me off treatment and leave me home to die.” (Male, 17 years).

However, most of our participants received emotional support from their fellow patients, especially those who had improved during treatment. Through their casual chats while on the ward, they helped to dispel the fear that cancer cannot be successfully treated.

“Initially, my mother believed that cancer was not curable, so she had lost hope and wanted return home. However, a random stranger in the ward, whose child had just recovered from cancer, came and encouraged her to stay hopeful because cancer is curable.” (Male, 10 years).

Finding support from health workers

Most participants reported having received immense support from health workers who were empathetic and offered emotional and practical support. They reported that the health workers provided a safe space for them to express their feelings, answered difficult questions, offered guidance, and provided information about the medications and procedures.

“The doctor was so respectful and truthful. He also took us through the whole medication process and explained every detail to us.” (Male, 17 years).

Delays in receiving appropriate care

Most participants first sought care from herbalists, witch-doctors, and spiritual leaders. Some were also delayed in primary health facilities where they were treated for different disease conditions before referral.

“Aahh! In April, before I came to this hospital, I was given herbal medicine. In the first week, they gave me a dose, and I finished it, but the illness intensified, and they told me to go back for more herbal medicine. I went there, but still the disease advanced, and that contributed to my delay in getting diagnosed and starting chemotherapy.” (Male, 17 years).

Changes in physical appearance, side effects of medicines, and physical suffering

Adolescents were concerned about the physical impact, including weight and hair loss, and changes in the appearance of their fingernails. The changes made them feel ashamed, and they could not freely mix with their peers. Some were also distressed about the interrupted education opportunities, hence the potential loss of a bright future. Pain was one of the commonly mentioned causes of suffering leading to emotional turmoil, especially during the early course of the disease.

“I lost my leg and I am not the same. I feel bad about it because I will never get my leg again. I feel ashamed because people feel pity for me (broke down and cried).” (Male, 13 years).

“I was big but now when I became sick, I became too thin. You see I was weighing about 50kgs but now they weigh me and find that I have 27kgs, 20kgs.... don't you see that I have reduced a lot? So, I worry that it may fail to regain my original weight.” (17 years, male).

Pain is a complaint that almost every participant suffered in varying degrees, and this had profound effect in their activities of daily living, sleep quality and emotional pain. When pain was most intense, it signified severity of disease and diminishing chance of cure.

“For about two months, I was not able to sleep and would spend the whole night seated in one position because I would get pain on turning. I spent one month without eating well because whenever I would eat, stomach pain would worsen.” (17 years, male)

Discussion

This study was designed to explore the perceptions and experiences of adolescents with cancer in order to inform the formulation of interventions and support services

to adolescents diagnosed with cancer in our region and improve their care and quality of life.

Our study revealed that participants faced a very challenging period right from when the cancer symptoms set in and during the time of diagnosis and treatment. The challenges included the physical symptoms and psychological distress, plus the uncertainty of the future. They reported having missed out on everything that entails a normal adolescent life, like education and social relationships. However, most of the adolescents were hopeful for a cure from cancer, especially as they continued to interact with health workers who helped increase their knowledge of its curability and of the fact that they had a role to play in the management by having a positive outlook and being compliant with their prescribed management. The support they received from the health workers, relatives, friends, and religious leaders made the cancer journey more tolerable and hopeful.

Most participants were rightly not aware of the causes of childhood cancer since there are few known risk factors or ways to prevent childhood cancers. The DNA changes that most often cause childhood cancer are sporadic mutations [11]. However, most participants mentioned the commonly known risk factors for adult cancers, including unhealthy diet, smoking, and alcohol consumption. This finding indicates that adult cancer is more understood in our community than childhood cancer is, indicating the need to sensitize the community about childhood cancer, which usually has fewer preventable risk factors and needs a high index of suspicion to ensure early diagnosis [11, 12]. Most participants were able to name the various modalities of treatment of childhood and adolescent cancer, including chemotherapy, radiotherapy, and surgery. The most common source of this information is healthcare workers, which is delivered during the disclosure process, routine ward rounds, and counseling sessions. This finding is also in line with US-based research noting high factual knowledge about cancer causes and treatment among adolescents [13, 14].

Interacting with health workers has been shown to improve knowledge about cancer and debunk misconceptions [15, 16]. Continuous interaction with health workers and other patients with cancer led to cumulative knowledge about cancer over time. A study from South Africa showed higher knowledge about cancer among adolescents with a family or personal history of cancer [16].

Some participants in our study believed that cancer had supernatural causes, attributing it to God, curses, and spells from enemies, often seeking help from spiritual healers. This often led to delayed and/or interrupted utilization of medical care, contributing to poor outcomes. Spiritually oriented beliefs about cancer are common in this community and most of Africa, and

especially among the lower socio-economic populations [17, 18]. The results underscore the need for increased community awareness of biomedical causes of ill health and highlight the importance of building health systems that support a series of health-seeking behaviors that acknowledge both biomedical and local traditional healing belief systems.

Adolescents generally knew that cancer is a potentially curable disease and that medical treatment was effective. For many participants who initially held negative attitudes/beliefs about cancer, continued interactions with healthcare providers and improvement in symptoms on therapy were essential for change in beliefs. Even participants who were not assured of cure showed readiness to adhere to treatment. Similar studies in South Africa [19] and in the United States and Italy [13, 20] have also shown that most adolescents know that cancer is curable once proper health-seeking behaviors are in place.

Some participants thought that cancer is incurable. This was most evident among those who witnessed fellow patients dying and among participants who had recently begun treatment, likely because they were undergoing more intensive periods of treatment and associated side effects at the time of interview. A study in the USA noted similar findings of more negative attitudes when the symptoms of the disease were severe [21]. Similar findings were noted to be about the incurable nature of cancer, and this is common in LMICs where efforts to sensitize people about cancer are inadequate [22].

In our study, pain was one of the commonly mentioned causes of suffering leading to physical and emotional turmoil among adolescents with cancer. This has been reported in both HICs and LMICs [8, 23]. Unrelieved pain can lead to reduced quality of life, emotional disturbance, loss of sleep, and treatment adherence. Pain is generally poorly controlled in LMICs because of limited access to pain medications. This indicates the need to train health workers in pain management and provision of potent painkillers with fewer side-effects. Emotional disturbances, including symptoms suggestive of depression, were reported in this study, like in one at Uganda Cancer Institute (UCI), in Kampala city, Uganda, where depression rates of 25% were reported among children undergoing cancer treatment [24]. Similarly, in Iran, 50% of children with cancer aged 7–17 years had anxiety and depression disorders [25]. Emotional disturbances such as depression negatively affect the immunity but also reduces the likelihood of compliance to care among sick people, and overall quality of life.

Furthermore, adolescents in our study were distressed about changes in their physical appearance. A study in Zambia also revealed that adolescents were distressed about their changed physical appearance and leading to loss of confidence and social isolation. Specifically,

amputation has been cited as the most impactful of all physical changes [26]. Physical appearance is very important to adolescents because of its impact on self-esteem, social relationships, and overall mental health, and much input including proper nutrition, prosthetics, counseling, and involvement of cosmetic professionals, is needed to preserve the appearance of adolescents with cancer.

As in our study, studies in the USA [27] and Kenya [28] described challenges in accessing education during and after cancer care, which negatively affected social inclusion. This made them uncertain of their future and life opportunities even after their cancer was cured. His condition can reduce the will to live; however, participants identified health care workers, family, and friends as key sources of social support during cancer care. The support from these people is a key determinant of survival in children and adolescents with cancer [29].

Limitations

The study was carried out in one PCU and hence may not satisfactorily represent all adolescents with cancer within our setting. However, this was helped by the fact that the PCU of MRRH is serving the whole of south-western Uganda.

Most of the younger participants were not able to sustain conversations for adequate period of time for the research team to obtain in-depth information about the topic, hence, most of the study's substantive information was obtained from older adolescents.

Conclusion

Adolescents' perceptions and experiences toward their cancer diagnoses vary significantly throughout the care continuum. Those who witness or experience negative events, such as the death of a fellow patient during treatment or personal intense disease symptoms, are more likely to have poor perceptions. The experiences and perceptions of adolescents are worse during the initial period of the disease and care. This usually corresponds to the intensely challenging period when disease symptoms and treatment toxicities are most intense.

Clinical implications

There is an urgent need for hospitals to provide professional counselling services to all adolescents receiving cancer treatment and their caretakers. Additionally, patients' knowledge and perceptions about cancer need to be revisited throughout the entire care continuum to address misconceptions and questions that arise. Children with severe symptoms and those likely to die need to be nursed in separate wards where the other children are unlikely to witness their suffering and death. The community needs to be further sensitized about the causes and common symptoms of cancer, to enable early

suspicion and diagnosis, and reduce social stigma around a pediatric cancer diagnosis.

Abbreviations

LMICs	Low- and Middle-income Countries
WHO	World Health Organization
MRRH	Mbarara Regional Referral Hospital
PCU	Pediatric Cancer Unit
MUST	Mbarara University of Science and Technology
REC	Research Ethics Committee
DNA	Deoxyribonucleic acid
HICs	High income Countries
UCI	Uganda Cancer institute

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions

Conceptualization: Mercy Akambasisa, Barnabas Atwiine, Kemigisha Elizabeth, Godfrey Rukundo Zari Data curation: Mercy Akambasisa, Barnabas Atwiine, Kemigisha Elizabeth, Godfrey Rukundo Zari, Carpenter Kendall. Methodology: Mercy Akambasisa Project administration: Mercy Akambasisa. Supervision: Barnabas Atwiine, Kemigisha Elizabeth, Godfrey Rukundo Zari Writing- original draft: Mercy Akambasisa, Barnabas Atwiine. Writing- review and editing: Mercy Akambasisa, Kendall Carpenter, Barnabas Atwiine, Kemigisha Elizabeth, Godfrey Rukundo Zari. Approval of the submitted work for publication: Mercy Akambasisa, Barnabas Atwiine, Kemigisha Elizabeth, Godfrey Rukundo Zari, Carpenter Kendall.

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Data availability

Available on request. To make requests, email to [akambasisa@gmail.com] (mailto: akambasisa@gmail.com).

Declarations

Ethics approval and consent to participate

Ethical approval was obtained from the Faculty of Medicine Research Committee (FRC) and Mbarara University of Science and Technology Research Ethics Committee (REC). Administrative clearance was obtained from the Hospital Director in order to conduct the study at MRRH. The study was registered with the Uganda National Council for Science and Technology. Informed consent was sought from the caretakers/ parents of participants and informed assent was sought from the participants for the In-depth interviews and audio recordings. In case of child dissent, it took precedence over the caretaker's consent. This being a sensitive study, it was expected that negative emotions may arise during the interview, and in case this occurred, the interview would be stopped, and the participant would be given time to recover (one hour). If this would not happen, such a participant would be sent to a professional counsellor who was also part of the study team and would be asked to offer appropriate care to such a participant. This study adhered to the World Medical Association Declaration of Helsinki.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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