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CASE REPORT

Late Effects of Therapy, Stigmatization and Social Reintegration following Childhood Cancer Survival in Kenya: A Case Report

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Summary

Childhood cancer survival is increasing in low- and middle-income countries like Kenya, which comes with a new healthcare challenge: late effects and quality-of-life of survivors. A case was studied to depict a Kenyan Hodgkin lymphoma survivor, illustrating some of the childhood cancer survivors' difficulties in Kenya. Late effects of therapy, stigmatization and social reintegration were explored. The investigators reviewed medical records and used semi-structured interviews and stigma assessments using the Social Impact Scale. The survivor developed severe pulmonary hypertension during treatment with ABVD and salvage protocols. Three years after treatment, the patient experienced chemotherapy-induced late effects (chronic heart disease) that hindered personal care, social activities and job opportunities and required follow-up. Stigmatization by the community burdened his family life and marital prospects. This case report is one of the first that testifies of combined medical and psychosocial challenges that childhood cancer survivors may face in sub-Saharan Africa and underlines the need for a holistic approach.

Keywords:* *Childhood cancer survivors, Hodgkin Lymphoma, Low and Middle-Income Countries, Social Reintegration, Stigmatization.

Introduction

Childhood cancer has become a curable disease in high-income countries (HIC), with survival rates approaching 80%. [1] The majority of childhood cancer patients in HIC will survive into adulthood. Studies show that survivors not only suffer from late effects, like cardiotoxicity and infertility but also from stigmatization. [2, 3] Social reintegration of these children in school, career and relationships is also hampered. [4] These challenges may adversely impact the quality of life. [5]

In low- and middle-income countries (LMIC) like Kenya, the survival of common childhood cancers is often below 30%. [6] Initiatives to encourage timely referral, reduce abandonment, and implement adapted treatment protocols to fit local settings are slowly improving survival rates. [7] At the Moi Teaching and Referral Hospital (MTRH), a tertiary-care referral hospital in Western Kenya, childhood cancer survival rates have continuously increased over ten years. [7] This comes with a new healthcare challenge: late effects and quality-of-life of survivors. Future health risks of cancer treatment are not thoroughly discussed with survivors during standard care, and late effects monitoring depends on individual interpretation of guidelines used in HIC. [8] Stigma, myths and misconceptions about cancer play a significant role in the social rejection of affected children, particularly in LMIC, where education and knowledge about health issues among the general public are limited. [9, 10] Follow-up adherence of survivors is generally low and affected by financial status. [11, 12] Therefore, our understanding of the late effects and quality-of-life of childhood cancer survivors is limited in Africa.

At MTRH, insight into the late effects of therapy, stigmatization and social reintegration of childhood cancer survivors is also lacking. This information may help guide the long-term management of affected children. This case report investigates difficulties that Kenyan childhood cancer survivors and their families may face during and after successful treatment completion, considering the late effects of therapy, stigmatization and social reintegration.

Methods

Setting

Kenya is an LMIC where 36% of the population lives below the poverty line. This study was performed at MTRH, where an average of 200 children are diagnosed with malignancies annually. Chemotherapy, surgery and radiotherapy are provided, and these services are covered by National Hospital Insurance Fund (NHIF). [6]

Study Design

A case report was conducted, combining a review of medical records, a semi-structured interview and stigma assessment done through the Social Impact Scale to highlight the challenges Kenyan childhood cancer survivors face. Late effects of therapy, stigmatization and social reintegration were studied. The investigators identified a Hodgkin lymphoma survivor at the Oncology Clinic and examined his medical records. The survivor was interviewed at MTRH in December 2021. Two independent interviewers used a semi-structured questionnaire based on an extensive literature review. [4, 13, 14] Stigma was measured with Fife and Wright's Social Impact Scale (SIS). This scale distinguishes three subscales: Social Rejection, Internalized Shame and Social Isolation. Higher scores on that scale correspond with a more severe perception of stigmatization. [13] In March 2022, the respondent was contacted for further clarification and contextualization of perspectives and experiences. The survivor gave informed consent and endorsed the report.
The Moi Teaching and Referral Hospital Institutional Research Ethics Committee approved this study (Approval number - FAN:0004007)

Case Description

A sixteen-year-old boy had noticed an increasing neck swelling and cough of a year duration. He presented at a district hospital with dyspnoea and palpitations in early April 2018, where he received treatment for pulmonary tuberculosis. When his symptoms persisted, a lymph node biopsy was performed, confirming the diagnosis of Hodgkin lymphoma in May 2018. The boy was subsequently referred to MTRH.

At MTRH, the patient presented with fever and required oxygen supplementation. Blood count showed anaemia with leucocytosis and thrombocytosis. Renal and liver functions were normal. Chest X-ray showed right pleural effusion. The sputum test for tuberculosis was negative. Baseline echocardiography revealed mild pulmonary hypertension with normal right and left ventricular functions before chemotherapy. Enlarged para-aortic lymph nodes and ascites were detected on abdominal ultrasound scanning. Subsequently, cytotoxic therapy according to ABVD protocol [Adriamycine, Bleomycin, Vinblastine, Dacarbazine] was commenced. Two months later, his treatment was stopped after three courses of chemotherapy as echocardiography showed right heart failure and severe pulmonary hypertension. Therapy with the Salvage protocol [Cyclophosphamide, Etoposide, Vincristine and Prednisone] was subsequently substituted for three additional courses. (Table I).

Table I: Chemotherapeutic agents used in the childhood cancer survivor and their known late toxicities

ABVD Protocol*		**Salvage Protocol****	
Chemotherapeutic Agents (Class)	Known Late Toxicity	Chemotherapeutic Agents (Class)	Known Late Toxicity
Adriamycin (Anthracyclines)	Cardiac (Cardiomyopathy or Arrhythmia)	Cyclophosphamide (Alkylating agents)	Fertility (Azoospermia/ Premature ovarian failure) Renal (chronic kidney disease)
Bleomycin (Cytostatic antibiotics)	Pulmonary (Restrictive lung disease) Fertility (Azoospermia / Premature ovarian failure)	Etoposide (Topo-isomerase II Inhibitor)	Secondary malignancy (Second new type of cancer)
Vinblastine (Vinco-alkaloids)	Neurological (Peripheral neuropathy)	Vincristine (Vinco-alkaloids)	Neurological (Peripheral neuropathy)
Dacarbazine (Alkylating agent)	Fertility (Azoospermia/ Premature ovarian failure)	Prednisone (Corticosteroids)	Orthopaedic (Osteoporosis) Ocular (Cataract)

* **ABVD-protocol**: Six cycles of Adriamycin (25 mg/m^2 on days 1 and 15), Bleomycin (7.5 mg/m^2 on days 1 and 15), Vinblastine (6 mg/m^2 on days 1 and 15) and Dacarbazine (375 mg/m^2 on day 1 and 15) every four weeks.
** **Salvage-protocol:** Six cycles of Cyclophosphamide (750 mg/m^2 on days 1 and 8), Etoposide (80 mg/m^2 on days 1, 2 and 3), Vincristine (1.4 mg/m^2 on day 1) and Prednisone (60 mg/m^2 for five days) every 3/4 weeks.
Co-medication: Vasodilators (Sildenafil), Antihypertensives (Enalapril/Furosemide) and Inotropes (Digoxin)

The boy lived with his parents as the second among four children. His father was a casual labourer, while his mother was a farmer. Although NHIF covered medical expenses, recurring travel costs burdened the family and led to parental conflicts.

Before the cancer diagnosis, the boy enjoyed a lively social life. The attitude of relatives, neighbours and friends changed drastically during his cancer diagnosis and treatment. His conjugal family was avoided because they feared cancer was a contagious curse.

Hospitalizations and the side effects of therapies caused frequent school absences. The teacher disclosed his illness to his fellow students, but he felt unprepared to discuss his condition as he was afraid to be ignored or discriminated against. He had trouble interacting with other children, who feared coming closer to him and getting infected with cancer. After five months, the boy completed the treatment and was discharged in clinical remission.

The young man attended the clinic for follow-up care for three years following the completion of treatment. He was monitored at the cardiology clinic every four months for pulmonary hypertension, which also required daily ingestion of cardioprotective medication (Bosentan®). The latest echocardiography showed a dilated right atrium with elevated right ventricular systolic pressure. The pulse rate and blood pressure were normal. He also visited the oncology clinic annually. Fatigue and chest pain often occurred during exercise. He had physical restrictions in personal care (like showering and dressing) and social activities (like church visits and exercising). These limitations got him worried and sad, as reflected on the Social Isolation subscale (Table II).

After completing the treatment, the boy resumed schooling, but his physical condition forced him to miss classes and rest at home. Judgements about his appearance, referring to his hair texture, nails and weight loss, made him keep away from his classmates. He isolated himself and had difficulty sleeping. Accordingly, he recorded high Social Rejection and Social Isolation scores (Table II). Although he graduated from primary school, financial problems stopped him from completing secondary school, so he became unemployed. Job options were also limited since he could not perform heavy labour due to his exercise intolerance due to heart disease.

The rejection by his relatives remained unchanged despite achieving remission. They visited less frequently and gossiped about him in the community. When they passed by his house, they preferred not to share dinner or sleep in the same building with him because they regarded cancer as an incurable transmittable disease. His parents were also recently divorced, and the cancer history and the financial difficulties involved might have played a role in their separation. Feelings of blame about these events were expressed in the boy's performance on the Internalized Shame subscale (Table II).

The young man remains single and afraid that the stigma about infertility and heritability affects his marital prospects. He thinks that he and his immediate family are less likely to get married because other people fear that childhood cancer is heritable and his family is cursed. This might discourage a future partner from starting a relationship. He is anxious that neighbours will spread rumours to separate him from his future spouse or expel them from the village.

Evaluation

Despite stigmatization, the young man no longer wants to keep his cancer history a secret. This conscious decision to be open about his previous illness is also illustrated by his disagreement with several statements on the Internalized Shame subscale (Table II). He wants to teach other patients that cancer is not a death sentence and thus encourage them to speak out and raise awareness about childhood cancer.

Table II: Stigmatization of childhood cancer survivor according to the Social Impact Scale

Sub-scales	*Strongly Agreed (4 points)*	*Agreed (3 points)*	*Disagreed (2 points)*	*Strongly Disagreed (1 point)*
Social Rejection				
- Some people act like I am less competent due to previous illness	X			
- Others treat me with less respect than usual	X			
- Others are concerned that cancer is contagious	X			
- Others avoid me because of my previous illness	X			
- Some family members rejected me because of previous illness	X			
- Some friends rejected me because of my previous illness	X			
- I encounter embarrassing situations due to previous illness		X		
- Others seem awkward and tense around me	X			
SCORE (8-32): 31 points				
Internalized shame				
- Others blame me for my previous illness	X			
- I do not feel I can be open with others about my previous illness				X
- I fear that someone is telling others about my previous illness without my permission	X			
- I feel the need to keep previous illness a secret		X		
- I feel that I am at least partially to blame for my previous illness				X
SCORE (5-20): 13 points				
Social Isolation				
- I feel different from others who have always been healthy	X			
- I have a greater need than usual to hear that others care about me	X			
- I feel lonely more often than usual		X		
- I feel less worthy in social relationships (friend/family/ romantic)		X		
- I feel less competent than before I got ill	X			
- Due to illness, I sometimes feel useless	X			
- Changes in my appearance have affected my social relationships (friend/family/romantic)	X			
SCORE (7-28): 26 points				

Discussion

Survival in childhood cancer is slowly but steadily increasing in LMIC. This coincides with a shift in medical attention towards the late effects of therapy and quality-of-life of survivors. This case report is one of the first that describes the medical and psychosocial challenges that childhood cancer survivors may face in sub-Saharan Africa. It depicts a young man who, after surviving a life-threatening condition, still faces the long-term consequences of his previous ailment, including the late effects of chemotherapy and serious stigmatization by his community.

After chemotherapy with anthracyclines and alkylating agents, this survivor became a chronic heart disease patient suffering from various physical complaints, like fatigue and pain. Studies from HIC reported that almost 75% of survivors experience adverse health events following childhood cancer treatment. Receiving anthracyclines, especially combined with alkylating agents, significantly increases the risk of cardiovascular disease and infertility. [2] In a cohort of Egyptian children with Hodgkin's disease, 50% had impaired cardiac function after finishing the ABVD protocol. [15] Infertility is a leading disabling event affecting childhood cancer survivors in HIC. [2]

Besides experiencing physical late effects of chemotherapy, the survivor and his conjugal family were judged and avoided by relatives, friends and villagers, not only after diagnosis but also after treatment. The community believed that cancer is incurable, contagious and a ‘curse’. High stigma scores were assessed, especially on social rejection and social isolation subscales. Previous studies in HIC had described stigmatization and educational, career and marital obstacles encountered by childhood cancer survivors. [3, 4, 13]

Literature on childhood cancer survivors in LMIC is scarce because most children still succumb to cancer in LMIC. It mainly focuses on the somatic late effects of therapy. [15] However, the psychosocial impact of surviving cancer should not be neglected. Although the presented evidence is anecdotal, its alarming nature underlines the need for a holistic approach and justifies further exploration. After all, the long-term aim of curing childhood cancer is to provide the opportunity for children to become worthy and equal members of society. Future research is urgently required on the extent and nature of these late effects, stigmatization, and social reintegration involving more childhood cancer survivors.

Advocacy for a holistic approach in guiding the well-being of childhood cancer survivors is required to map, minimize and prevent the late effects of therapy. Adapted follow-up guidelines must also be integrated into standard care in LMIC. [8, 14] Risk groups should be identified and monitored closely, whereas, for low-risk survivors, less stringent surveillance like telephone check-ups may suffice. In addition, advocacy is required to prevent stigmatization and facilitate social reintegration, as cancer myths and misconceptions need to be eradicated. [9, 10] Both patients and communities should be addressed. National awareness campaigns, developing educational materials on survivorship, and training of psychosocial counsellors and peer support groups are warranted. This combined approach could empower survivors to cope better with the late effects of therapy and stigma, which ultimately helps to improve their quality of life.

Study Limitation

This study, addressing one case from one hospital and country, requires caution with generalization.

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Conflict of Interest: None declared.

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