

Title: Quality of Life and Lived Experiences of Adolescent Cancer Survivors aged 10-19 years at Mbarara Regional Referral Hospital

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Abstract

Background: Adolescent cancer survivors are at increased risk of poor quality of life and most of them are affected by the experiences right from cancer diagnosis throughout their survivorship. Despite this, the quality of life and lived experiences of adolescent cancer survivors in Africa including Uganda, is still unknown.

Aim: This study aimed at evaluating the Quality of life and documenting the lived experiences of adolescent cancer survivors at Mbarara Regional Referral Hospital.

Methods: We conducted a cross sectional convergent parallel mixed methods study among adolescent cancer survivors. WHOQOL-BREF questionnaire was used to assess their quality of life. We Purposively sampled and conducted in-depth interviews to get their lived experiences.

Results: Quantitative results: A total of 42 participants were consecutively enrolled. The mean age was 13.2±2.9 years and 55% were males. Most participants had survived Hodgkin lymphoma (33%) and Wilm's tumor (19%). Participants rated their quality of life as poor (2.4%), good (69.1%) and very good (28.6%) and were satisfied (71.4%) or very satisfied (26.2%) with their health. Participants were dissatisfied with their sleep (60%) and ability to perform their daily living activities (76%). **Qualitative results:** 20 in-depth interviews were conducted. The median duration of survivorship was 2 years with IQR of 2. Two themes emerged, negative and positive lived experiences. The negative lived experience had subthemes such as career change and lost need for career advancement, concerns of appearance and cosmesis, family separation, current expenditure and financial crisis, fear of cancer relapse, reduced energy and limitation of physical activities. The positive lived experiences had subthemes such as persistent gratefulness, living hope for cure of childhood cancer, relationship restructuring and power of religious leaders.

Conclusion: The quality of life of adolescent cancer survivors at MRRH was good with impairment only in the physical domain. Family support and health workers play a great role.

Recommendation: Targeted interventions such as psychosocial services for all cancer survivors and a cancer survivors club to promote peer support and recovery during survivorship.

Keywords: Adolescent. cancer survivor. Lived Experiences. Quality of life