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Reproductive Concerns and Associated Factors Among Adolescent and Young Adult Cancer Survivors in Uganda: A Hospital-Based Cross-Sectional Study

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Purpose: Reproductive health (RH) is a critical issue among cancer survivors worldwide. However, in developing countries where RH services for patients with cancer are often lacking, reproductive concerns among adolescent and young adult (AYA) survivors remain uncertain. In this study, we assessed the reproductive concerns of AYA cancer survivors in a resource-limited context of Uganda.

Methods: We collected data from AYA cancer survivors at two facilities in Uganda using an interviewer-administered questionnaire. Descriptive statistics were calculated, one-way analysis of variance was used for intergroup comparisons, and multiple regressions were used to test for predictors of reproductive concerns.

Results: A total of 110 AYA cancer survivors, with a median age of 20 years (interquartile range [IQR], 18–22), were interviewed. More than half (53.6%) of the respondents were males. The median time since cancer diagnosis was 19 months (IQR, 13.0–35.0). Almost all (91.8%) respondents had a future desire to have children, but only 15.5% received reproductive counseling. The mean total score for the reproductive concern subscales was highest for the fertility concern, followed by the information-seeking and health-related concerns. Reproductive counseling, desire to have children, and respondents' age were the factors influencing reproductive concern.

Conclusions: The study shows a strong desire for biological parenthood with very low reproductive counseling among AYA cancer survivors, who remain concerned about their fertility, information needs, and health. This outcome underscores the need to integrate RH services into resource-limited cancer care settings.

Keywords: reproductive health, concerns, adolescents and young adults, cancer survivors

Introduction

Reproductive health (RH) ranks as one of the most critical issues among adolescent and young adult (AYA) cancer survivors,¹ cited by 20%–68% of survivors.^{2–4} Recent advances in cancer treatment have resulted in significant improvements in cure rates and survival. Infertility

and poor reproductive outcomes are among the most significant reproductive challenges associated with successful cancer treatment and have a considerable impact on survivors' quality of life.^{1–5} Cancer and its combined therapeutic modalities can interfere with normal developmental trajectories and may compromise fertility outcomes in survivors.^{6,7}

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Emerging shreds of evidence show that adolescents with cancer have specific RH needs and concerns,^{1,8} and yet lack relevant knowledge concerning the disease affecting their sexuality.⁹ These concerns are multidimensional, encompassing fear of cancer recurrence, acceptance by peers, psychological stress, and the health of the child and partner.^{10–12} Altered body image perceptions, infertility, and the desire and hope for biological children and parenthood^{13,14} are the other concerns, among others.

While fertility preservation has become increasingly important to improve the quality of life for cancer survivors, in developing countries, these services are grossly lacking in addressing AYA survivors' reproductive needs. The broader RH issues facing AYA cancer survivors, particularly in resource-limited settings, are, however, often neglected,⁷ a consequence of a combination of clinicians' discomfort addressing infertility and parental protective buffering.^{15,16}

In Uganda, where treatment modalities for cancer include cytotoxic chemotherapy, radiation therapy, and surgery—all impacting reproductive outcomes, RH services for cancer survivors are at present not available. To date, the literature on RH issues among AYA cancer survivors in low-resource settings remains scanty. In Uganda, RH issues in this group have remained a nonpriority, and interest in this area has only recently emerged.^{17,18} Identifying the RH needs and concerns of AYA cancer survivors is an essential first step to inform a call to action for addressing the long-term RH goals and quality of life in survivorship. The objective of this study was to assess RH needs and concerns among AYA cancer survivors in Uganda.

Methods

Study design and study setting

This was a cross-sectional study conducted at two centers in Uganda: the Uganda Cancer Institute (UCI) and St. Mary's Hospital Lacor, between November 2022 and May 2023. This design was chosen to gain valuable insights and offer baseline data on the subject matter. UCI is the national reference cancer treatment center, treating about 400 new childhood cancer cases (approximately 80% of children with cancer in Uganda) annually. St. Mary's Hospital Lacor is a tertiary private not-for-profit faith-based facility in northern Uganda. It's approximately 330 km north of Kampala, Uganda's capital city, and the only cancer treatment center in the northern region. At both sites and in Uganda as a whole, there are no fertility preservation options for cancer survivors.

Study population

The study population comprised AYA cancer survivors of ages 18–24 years. We defined a cancer survivor as an individual treated for cancer who is still alive at least 6 months after cancer-specific therapy. Respondents with all cancer types were considered. Stable survivors were included, while those who were unstable, had missing files, or declined consent were excluded.

Sample size estimation

The sample size was estimated using the single population proportion formula by Kish Leslie (1965)¹⁹ based on the rate of reproductive concerns among cancer survivors (P) of 60%,³ with a marginal error (D) of 5%, and a standard normal value (Z) corresponding to 95% certainty (1.96), giving a sample size of 369. Given that the estimated number of AYA cancer survivors at the two study sites over the past 5 years from a preliminary survey was about 140, and adjusting for a finite population, the adjusted sample size was 102, and we recruited 110 participants.

Sampling procedures

The selection of the study participants was based on a convenience sample of AYA cancer survivors during their routine follow-up clinic visits.

Data Collection

Study instrument

A structured questionnaire was used to collect quantitative data, sectioned into baseline sociodemographic characteristics, disease-related information, and RH information. In addition, the 10-item Modified Reproductive Concerns Scale (mRCS)²⁰ was used to assess survivors' reproductive concerns. The total scores ranged from 10 to 50 points, with each item assessed on a 5-point Likert scale, where 1 = Not at all, 2 = A little bit, 3 = Somewhat, 4 = Quite a bit, and 5 = Very much. Higher scores indicated a stronger agreement with the item as a concern. The reliability of the RCS tool has been validated, with a Cronbach's reliability coefficient of 0.91.²¹ Three subscales from the mRCS representing three dimensions of reproductive concerns have previously been established, including fertility concerns ($\alpha = 0.77$), illness concerns ($\alpha = 0.74$), and information seeking ($\alpha = 0.57$).²⁰

Recruitment procedure

Study participants were identified at the clinics by the research assistants—clinicians involved in managing the patients at each of the sites, and have developed clinician–patient relationships and trust, enabling free expressions of opinion by the participants. The purpose of the study was explained, and informed consent was obtained from the participants for their participation in the study. Each consented participant then had a questionnaire administered by the study clinician in a face-to-face interview to collect sociodemographic information, cancer diagnosis and treatment, the number of years since diagnosis, RH concerns, and RH counseling (before, during, and after treatment). Cancer treatment data were abstracted from participants' medical records.

Measurements

The outcome variable was survivors' RH concern, and the predictor variables included demographic characteristics (age, gender, religion, level of education), disease information (cancer diagnosis, time since diagnosis), and RH counseling.

Data management and analysis

Data were entered, cleaned, and analyzed using Statistical Package for Social Scientists (SPSS) version 23. Descriptive statistics were calculated, including means (standard deviations) and medians (interquartile ranges) for continuous variables and frequencies and percentages for categorical variables. One-way analysis of variance was used for intergroup comparisons, and multiple regressions were used to test the factors independently influencing reproductive concerns among the AYA survivors. The level of statistical significance was set at 0.05. No specific subgroup analysis was performed.

Ethical considerations

All methods were carried out following relevant guidelines and regulations, and the study was conducted as per the Declaration of Helsinki. The study was approved by the Gulu University Research and Ethics Committee (GUREC-2022-343).

Results

Description of the study participants

During the study period, 110 AYA cancer survivors of age 18–24 years were recruited into the study (Fig. 1), over one-half (53.6%; 59/110) of whom were males.

The mean age of the study participants at study enrollment was 20.1 years (standard deviation [SD] 2.1), and the mean age at cancer diagnosis was 17.5 years (SD 3.8), with a range

of 6–24 years. The median time since cancer diagnosis was 19 months (interquartile range [IQR], 13.0–35.0), and the median time since initiation of cancer-specific treatment was 17 months (IQR, 11.0–29.3). More than half (54.5%) of the participants had attained secondary-level of education; 41 (37.3%) had primary-level education; and only 9 (8.2%) had achieved tertiary-level education. The most common cancer diagnoses were solid tumors (55.4%; $n = 61$), followed by lymphoma (29.1%; $n = 32$) and leukemia (15.5%; $n = 17$). With the exception of 9 participants who already had children, all the other 101 participants (91.8%) wished to have children in the future. Only 17 (15.5%) of all the respondents received RH counseling during their cancer treatment; nearly all of those who did not receive RH counseling ($n = 92/93$; 98.9%) wished they had (Table 1).

Reproductive concerns among AYA cancer survivors

The overall mean reproductive concern score in the study sample was 33.82 ± 7.34 , with the mean ranking scores of the three dimensions being as follows: fertility concerns (10.63 ± 2.73), information seeking (7.47 ± 1.84), and illness concerns (5.60 ± 3.10) (Table 2).

Factors associated with reproductive concern among the study respondents

The reproductive concern score was significantly associated with age at diagnosis ($p < 0.001$), age at the time of the study ($p = 0.001$), religious belief ($p = 0.035$), type of cancer diagnosis ($p = 0.010$), RH counseling ($p = 0.009$), and both

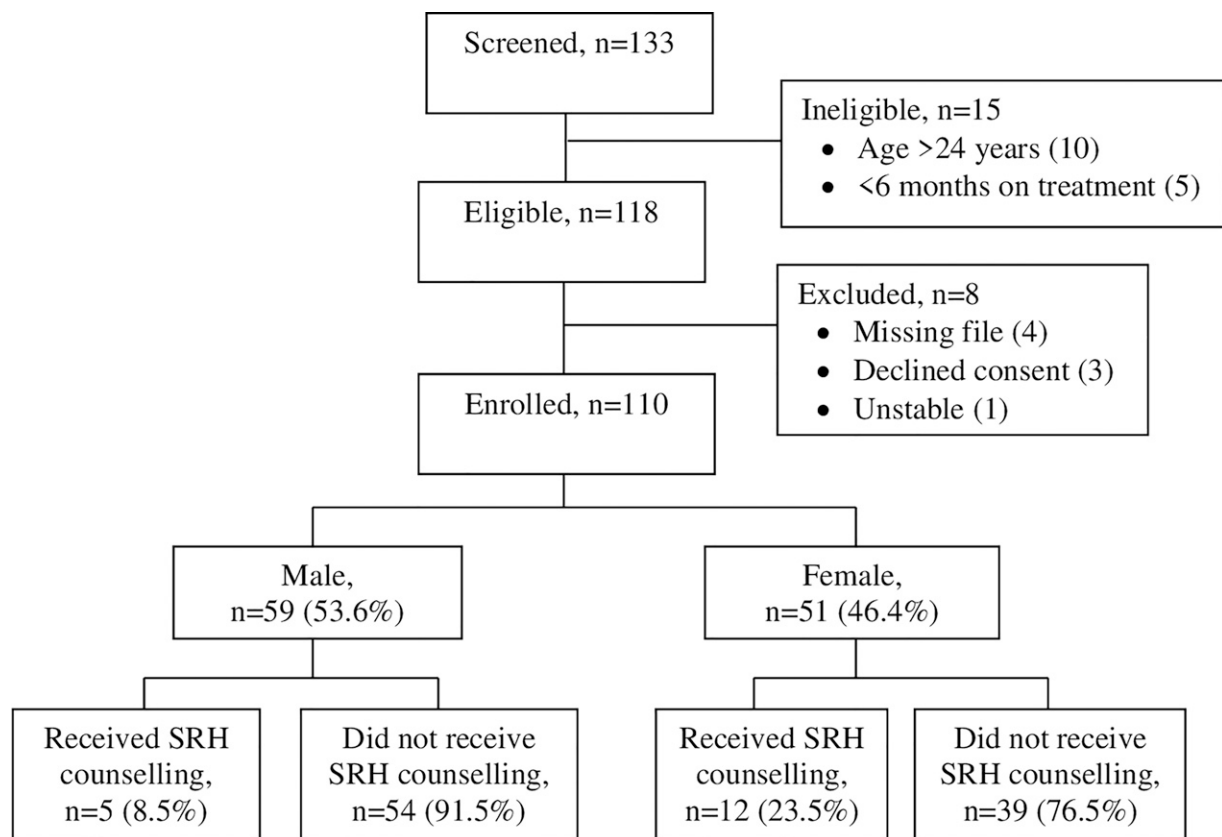


FIG. 1. Study profile. SRH, sexual and reproductive health.

TABLE 1. DESCRIPTION OF ADOLESCENT AND YOUNG ADULT CANCER SURVIVORS WHO WERE SURVEYED IN THE PERIOD NOVEMBER 2022–MAY 2023 ($N = 110$)

Characteristics	Mean	SD
Age at study participation (years)	20.1	2.1
Age at cancer diagnosis (years)	17.5	3.8
Time since cancer diagnosis (months) ^a	19.0	13.0–35.0
Time since cancer treatment (months) ^a	17.0	11.0–29.3
Sex		
Male	59	53.6
Female	51	46.4
Education level		
Primary	41	37.3
Secondary	60	54.5
Tertiary	9	8.2
Religion		
Catholic	52	47.3
Anglican/Pentecostal	43	39.1
Others	15	13.6
In a relationship?		
Yes	37	33.6
No	73	66.4
Cancer diagnosis		
Leukemia	17	15.5
Lymphoma	32	29.1
Solid tumors	61	55.4
Received reproductive counseling		
Yes	17	15.5
No	93	84.5
Desire to have children at present		
Yes	30	27.3
No	75	68.2
Not sure	5	4.5
Desire to have children in future		
Yes	101	91.8
No	3	2.7
Not sure	6	5.5

^aMedian (interquartile range).
SD, standard deviation.

present ($p < 0.001$) and future ($p = 0.001$) desire to have children (Table 3).

Factors independently predicting reproductive concern among the study respondents

On multiple linear regression analysis, the factors significantly associated with reproductive concerns among the study participants included age at the time of the study ($p = 0.026$), RH counseling ($p < 0.001$), and both present ($p = 0.004$) and future ($p = 0.015$) desire to have children (Table 4).

TABLE 2. REPRODUCTIVE CONCERN SCALE MEANS SCORE FOR THE AYA CANCER SURVIVORS IN THE STUDY

Subscale (items)	Mean \pm SD	Ranking
Fertility concerns	10.63 \pm 2.73	1
Illness concerns	5.60 \pm 3.10	3
Information seeking	7.47 \pm 1.84	2
Overall scale	33.82 \pm 7.34	/

SD, standard deviation.

Discussion

The aim of this study was to investigate the RH concerns among AYA cancer survivors in a low-resource setting and to determine the factors underpinning these concerns. This study offers an opening for closing the gaps in RH services existing in the study setting and other similar contexts. Key findings of this study include a strong desire for biological parenthood among the AYA cancer survivors, as well as a significant degree of concern about fertility, knowledge gap, and the influence their health may have on their reproductive lives. This underscores the need for the integration of RH services into cancer treatment in resource-constrained settings.

Nearly all (91.8%) of the AYA cancer survivors in the present study expressed a desire to have biological children in the future. This finding differs little from the 82% rate reported by Kayiira et al. in a registry-based study among survivors in Uganda.¹⁷ The finding is also similar to that observed among Dutch female cancer survivors²² and young male survivors in the United States.²³ This finding, which supports the significance of biological parenthood for AYAs surviving cancer, may not come as a surprise. While this is encouraging, it is also challenging for cancer care professionals in resource-constrained settings, such as Uganda, where there is limited capacity to offer RH services, including fertility preservation.

Interestingly, only 15.5% of the participants in the present study received reproductive counseling during their cancer diagnosis and treatment. This rate is significantly lower than has been documented in other contexts,^{23,24} but it supports a recent finding from Uganda, where up to 79% of survivors lacked satisfactory reproductive information before cancer treatment.¹⁷ Nearly all of the survivors in our study who did not receive counseling wished they had. This should be concerning given the negative impact that a lack of counseling has on psychological health during survivorship.²⁴ Compared with older adults, young survivors in particular, as is the case in the present study, tend to experience an increased risk of psychological distress with unmet informational needs.^{25–27} Unmet informational need has been advanced as a plausible conduit in the relationship between reproductive concerns and depression,²⁵ and failing to meet the informational needs of survivors may contribute to poorer quality-of-life outcomes.²⁸

Three subscales of reproductive concern have previously been established by the validation of the mRCS instrument. These subscales have been identified as priorities for survivors during emerging adulthood, and addressing them early is suggested to help reduce future fertility-related distress as the survivors age.²⁹ These subscales focus on fertility concerns, illness concerns, and information seeking. To find out the relative contributions of each subscale to reproductive concerns among our study population, we computed the mean scores of the items in the 10-item mRCS that correspond to each of the subscales. With the highest mean scores, fertility concerns were a major issue for the study respondents, supporting the notion that survivors' fertility following cancer treatment continues to be a serious concern, particularly with regard to having children in the future.^{30–32} Reproductive concerns and an unfulfilled desire to procreate can have a negative impact on cancer survivors' well-being if overlooked, resulting in depressive symptoms and a lower

TABLE 3. UNIVARIATE ANALYSIS OF STUDY VARIABLES

Characteristics	Frequency (%)	Score (mean \pm SD)	F/t-value	p value
Sex				
Male	59 (53.6)	33.17 \pm 7.50	0.129	0.721
Female	51 (46.4)	33.71 \pm 8.18		
Age at cancer diagnosis (years)				
<18	47 (42.7)	37.21 \pm 7.47	11.698	<0.001
18–19 (17.5–19.5)	29 (26.4)	30.28 \pm 7.08		
20–24 (19.5–24.5)	34 (30.9)	30.85 \pm 6.65		
Age at study participation (years)				
18–19 (17.5–19.5)	54 (49.1)	35.94 \pm 8.10	12.313	0.001
20–24 (19.5–24.5)	56 (50.9)	30.98 \pm 6.69		
Education level				
Primary	41 (37.3)	32.15 \pm 7.90	1.096	0.338
Secondary	60 (54.5)	34.42 \pm 7.82		
Tertiary	9 (8.2)	32.56 \pm 6.88		
Religion				
Catholic	52 (47.3)	31.52 \pm 7.78	3.466	0.035
Anglican/Pentecostal	43 (39.1)	35.65 \pm 7.40		
Others	15 (13.6)	33.60 \pm 7.66		
Being in a sexual relationship				
Yes	37 (33.6)	35.35 \pm 8.07	3.513	0.064
No	73 (66.4)	32.44 \pm 7.51		
Cancer diagnosis				
Leukemia	17 (15.5)	38.59 \pm 6.46	4.836	0.010
Lymphoma	32 (29.1)	32.00 \pm 7.53		
Solid tumors	61 (55.4)	32.72 \pm 7.79		
Time since cancer diagnosis				
\leq 12 months	26 (23.6)	31.77 \pm 7.76	1.533	0.218
12 months	84 (76.4)	33.93 \pm 7.78		
Received RH counseling				
Yes	17 (15.5)	37.94 \pm 3.98	7.161	0.009
No	93 (84.5)	32.59 \pm 8.04		
Desire to have children at present				
Yes	30 (27.3)	38.30 \pm 6.47	9.680	<0.001
No	75 (68.2)	31.75 \pm 7.38		
Not sure	5 (4.5)	29.20 \pm 9.50		
Desire to have children in future				
Yes	101 (91.8)	34.19 \pm 7.58	7.206	0.001
No	3 (2.7)	21.33 \pm 0.58		
Not sure	6 (5.5)	26.50 \pm 4.14		

Scores are presented as mean \pm SD and requisite test statistics and *p*-values are reported. RH, reproductive health. *P* values less than 0.05 are considered statistically significant and indicated in bold.

quality of life.^{21,33} As van Dijk et al. contend, infertility-related concerns should be minimized by promptly assessing the reproductive function following a cancer diagnosis before therapy begins and providing precise information about the risk of infertility and any available options.²² Proactively addressing this crucial survivorship problem for individuals who are at risk of infertility results in lower regret and an improved quality of life.²⁴

Information-seeking concerns ranked second among our study participants. The items in this subscale relate to survivors' interest in knowing how cancer diagnosis and treatment can affect their risk for infertility and if they can discuss potential infertility with their parents. This concern is consistent with a growing body of literature indicating that adolescents with cancer lack information and knowledge concerning how the disease and its treatment affect their

fertility.^{9,34,35} Lack of knowledge has been cited as the main obstacle to seeking RH services by cancer survivors,³⁶ yet this is an often overlooked component of care, especially in low- and middle-income countries. Common barriers to RH communication are believed to include low priority, lack of expertise on the part of health care practitioners, and discomfort on the part of parents, family, patients, and clinicians alike, among others.³⁷ In tandem with the aforementioned, we suppose one contributing factor to the information needs observed in our study is the lack of relevant institutional and national guidelines for the management of RH issues for patients with cancer and survivors. This calls for clear guidelines for oncological teams, particularly in low-resource settings, regarding the content, timing, and frequency of RH information for patients.^{7,38}

TABLE 4. MULTIPLE LINEAR REGRESSION RESULTS FOR FACTORS INFLUENCING REPRODUCTIVE CONCERN SCORE ($N = 110$)

Factors	B-value (95% CI)	SE	β -value	t-value	p value
Constant	69.705 (58.733, 80.676)	5.531	/	12.602	<0.001
Age at cancer diagnosis (years)	-1.707 (-4.060, 0.646)	1.186	-0.187	-1.439	0.153
Age at study participation (years)	-4.338 (-8.154, -0.522)	1.924	-0.280	-2.255	0.026
Religion	0.526 (-1.192, 2.224)	0.866	0.048	0.607	0.545
Cancer diagnosis	-0.430 (-2.107, 1.246)	0.845	-0.041	-0.509	0.612
Reproductive counseling	-8.808 (-12.378, -5.239)	1.800	-0.411	-4.895	<0.001
Desire to have children at present	-3.675 (-6.139, -1.211)	1.242	-0.245	-2.959	0.004
Desire to have children in future	-3.168 (-5.698, -0.638)	1.276	-0.195	-2.484	0.015

Note: Adjust $R^2 = 0.388$; $F = 10.865$; $p < 0.001$.

B, Unstandardized coefficients; CI, confidence interval; SE, standard error; t , t -statistic; β , standardized coefficients.

The health-related concern subscale among the study population had the lowest mean total score, but it nevertheless affirms other reports demonstrating that survivors worry about their own and their children's health.³⁹ This result is consistent with evidence that survivors' future reproductive decisions are influenced by concern about their health, including the possibility that their offspring may be more susceptible to cancer and other health conditions.^{3,10,40} Discussions regarding survivors' health risks and those of their offspring are therefore crucial.²⁰ This should include the reassurance that evidence does not suggest an increased risk for congenital anomalies among the offspring of childhood and adolescent cancer survivors.^{41,42}

The study found a significant association between RH counseling and reproductive concerns. This finding mirrors that reported by Young et al. among female AYA cancer survivors in North America, where, in comparison to survivors who did not get fertility counseling, those who did had a higher likelihood of reporting moderate to high concerns about their fertility (53% vs. 62%).⁴³ Despite its seeming contradiction, this finding suggests that counseling alone is not sufficient to address the spectrum of reproductive concerns in survivorship and may still result in low knowledge about fertility issues.¹⁵ This outcome underscores the need for more all-encompassing approaches to address the reproductive problems of AYA survivors, starting from the time of diagnosis and continuing through survivorship. Nonetheless, survivors have been reported to experience less regret and a higher quality of life after treatment when they get RH counseling.⁴⁴

The significant association between the desire to have children and reproductive concerns among the AYA cancer survivors in the present study may not come as a surprise, as previous studies have indicated that these concerns are higher among cancer survivors who expressed a desire to have a baby.^{13,45} It has been observed that unfulfilled dreams of having children following cancer treatment result in low mental health scores.^{46,47}

It has previously been documented that there is a relationship between the age of survivors and their reproductive concerns, with younger survivors being more likely than older survivors to have moderate to high reproductive concerns.⁴³ In the present study, survivors between the ages of 18 and 19 years had mean reproductive concern scores that were higher than that of survivors between the ages of 20 and 24 years, possibly because the younger survivors are often full of

dreams, yet are more likely to be childless at the time of their cancer diagnosis and treatment. Reproductive aspirations, an important factor that contributes to reproductive concerns in cancer survivors, may, nevertheless, have an impact on how age influences reproductive concerns.^{34,46}

The present study has limitations. We did not investigate prediagnosis reproductive intentions to see if there was a change due to a cancer diagnosis. However, we suppose that because many of the respondents could have been younger at the time of their cancer diagnosis, this preposition would not exactly suit. Second, because the study included survivors from only two centers, the findings may not be generalizable. It does, however, offer a unique perspective on the challenges of RH among cancer survivors in a resource-limited setting. One potential source of bias in this study was recall bias, in which respondents may not accurately recall information or be truthful. We minimized this by combining documented information from the respondents' files with the interviews.

Conclusions and Recommendations

AYA cancer survivors in Uganda have a strong desire for biological parenthood, but concerns about their fertility and health remain major issues. There is a high level of unmet information needs in the study setting. Survivors' age, desire for biological parenthood, and reproductive counseling have significant associations with reproductive concerns. There is, therefore, a need for integration of RH services into cancer treatment and care in settings with limited resources.

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Data Availability

The datasets generated and/or analyzed during the present study are available from the corresponding author on reasonable request.

Authors' Contributions

R.N. conceptualized and initiated the study, and contributed to the study design, data collection, and interpretation of results. N.O., C.J.A., P.A., B.A., C.K.N., P.O.M., and R.A. contributed to the study design, data collection, and revision and drafting of the article. F.G. supervised the study and reviewed the draft article. J.B. provided mentorship and critically revised the article. All the authors have read and approved the final article.

Author Disclosure Statement

The authors declare that they have no conflict of interests.

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