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Contraception Counseling and Use Among Adolescent and Young Adult Female Patients Undergoing Cancer Treatment: A Retrospective Analysis



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ABSTRACT

Study Objective: Adolescent and young adult (AYA) women undergoing cancer treatment face unique reproductive health risks. This study aimed to assess the prevalence of sexual health counseling and contraception use in the oncology setting, and to identify patient factors associated with these outcomes.

Design: Retrospective chart review.

Setting: Yale New Haven Hospital from 2013 to 2018.

Participants: Female patients 15-25 years of age receiving cancer treatment, excluding those treated with surgery only.

Interventions: None.

Main Outcome Measures: Outcomes of documented sexual health counseling and contraception use were assessed for frequency. Associations between patient factors and these outcomes were assessed using Pearson χ^2 and Fisher exact tests, and multivariate logistic regression was used to identify predictors of these outcomes.

Results: In this cohort (n = 157), the median age was 20.5 years, and the most common diagnoses were hematologic (40.8%) and thyroid (31.2%) malignancies. Of the patients, 33.1% were documented as receiving sexual health counseling, and 48.4% used contraception. Younger patients (15-20 years of age) were less likely to receive counseling (OR 0.31, 95% CI 0.14-0.70, $P = .005$). Receiving counseling (OR 3.36, 95% CI 1.35-8.34, $P = .009$) and sexual activity (OR 4.18, 95% CI 1.80-9.68, $P = .001$) were significantly associated with contraception use.

Conclusions: Sexual health counseling was documented infrequently during oncologic care for AYA women, especially for younger patients. However, such conversations were associated with a higher likelihood of contraception use. There is a need to improve rates of counseling in this high-risk setting, in which adolescents may be more vulnerable with regard to sexual health.

Key Words: Cancer, Adolescent, Young adult, Contraception, Sexual health, Reproductive health, Counseling

Introduction

Cancer among adolescents and young adults (AYAs) is relatively rare. In 2016, there were a total 1,658,716 new cases of cancer in the United States, of which 0.31% were among individuals 15-19 years of age, 0.49% were among those 20-24 years of age, and 0.83% were among those 25-29 years of age.¹ Despite the rarity of cancer diagnoses in this population, because of their age and sex, adolescent and young adult female cancer patients face unique challenges, especially with regard to sexual and reproductive health.

According to data from the Centers for Disease Control and Prevention (CDC) national Youth Risk Behavior Survey, 55.8% of female adolescents report having had sexual intercourse by the 12th grade.² It has been shown that AYAs with cancer engage in sexual relationships, often without

consistent contraception or protection from sexually transmitted infections (STIs).³ Among adolescents with cancer who report having had sexual intercourse in their lifetime, there is an increased rate of early-onset sexual intercourse, a greater number of partners, more current sexual activity, and less use of protection.⁴ Even among those using contraception, many in this population use less effective methods.⁵

Women undergoing cancer treatment face significant reproductive health issues. Chemotherapy and radiation can have toxic effects on oocytes and embryos, potentially leading to infertility, spontaneous abortion, or fetal anomalies.⁶⁻⁹ Education and counseling about reproductive and sexual health and access to contraception are therefore critical in the context of oncology care.

There is a need to better understand current patient and provider practices surrounding sexual health in this high-risk patient population. The aims of this study were, in a large tertiary care center, to determine the frequency of sexual health counseling provided by oncology providers to female AYA cancer patients receiving therapy; to determine the rates of contraception use in these patients; and to ascertain whether certain patient characteristics were associated with an increased or decreased likelihood of

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receiving such counseling or of using contraception. Although other studies have looked at rates of sexual health counseling and contraception use in groups of AYA cancer patients,^{5,10,11} none to our knowledge have examined how patient characteristics relate to both of these outcomes in this specific population. Obtaining information about the care currently provided to female AYA cancer patients will lead to a clearer understanding of unmet needs and will highlight possible opportunities for intervention.

Materials and Methods

Study Population

Approval was obtained from the Yale Institutional Review Board, after which a retrospective chart review was conducted. The Joint Data Analytics Team at Yale compiled a list of medical records fitting inclusion criteria for the study using information such as age, sex, and International Classification of Diseases, Tenth Revision (ICD-10) diagnosis codes for any type of cancer. Electronic medical records (EMR) were then manually reviewed to confirm eligibility and to gather data. Only patients who met all eligibility criteria based on manual medical record review were included in the final analysis.

Inclusion criteria for the study required patients to be female, between the ages of 15.0 and 25.99 years, with a new diagnosis of malignancy between the years 2013 and 2018, and receiving initial cancer directed therapy at Yale New Haven Hospital. Cancer treatment modalities included surgery, radiation, chemotherapy, hormone-based therapy, targeted or biologic treatments, and bone marrow transplantation. Patients treated with surgery alone were excluded from this study. Other exclusion criteria included a history of hysterectomy or removal of both ovaries and/or fallopian tubes prior to cancer diagnosis or as the first stage of treatment, as well as being pregnant at the time of the cancer diagnosis.

Variables and Data Collection

Primary outcomes assessed in this study included documented sexual health counseling by an oncology provider, as well as contraception use. Sexual health counseling was defined as documentation in the EMR of a conversation related to contraception use or pregnancy prevention during cancer treatment. Contraception use was defined as documentation of condoms and/or prescription contraception of any kind being used during the treatment period.

Other information gathered from the EMR, and included in this analysis as independent variables, included demographic data, types of cancer diagnosis and treatments received, obstetric history, specific contraceptive methods used, and sexual history. Documented sexual health counseling was considered in this study both as a dependent variable and as an independent variable in its relation to contraceptive use.

Medical records were reviewed starting from the initial diagnostic workup through remission or death, whichever occurred first. To extract data from the medical records,

provider notes were reviewed, as well as designated areas of the EMR for sexual history. In addition, the medical records were searched using predetermined search terms to ensure that information was not missed. These search terms included the following: sex, sexual, sexually, sexual activity, sexually active, condom, barrier, contraception, contraceptive, birth control, OCP, IUD, Mirena, Paragard, Depo, implant, Nexplanon, pregnant, and pregnancy.

Statistical Analysis

Frequencies were calculated for all independent and dependent variables. Bivariate associations between each independent variable and the outcome variable of documented sexual health counseling were assessed using Pearson χ^2 and Fisher exact tests. Multivariate logistic regression models were then constructed to identify predictors of the outcome of documented sexual health counseling. Variables with *P* values < 0.2 on univariate analysis were entered into the multiple logistic regression model. The variable of age was also included in the multivariate analysis on the basis of clinical significance. The same process was repeated for the dependent variable of contraception use.

Associations in the multivariate model between independent variables and the outcomes of receiving counseling or using contraception were reported as odds ratios (OR) with 95% confidence intervals (CI), and level of significance considered to be at $\alpha = .05$. Statistical analysis was completed using Stata version 15.0 (StataCorp, College Station, TX).

Sample size adequacy was determined based on the rule of thumb for logistic regression that for each independent variable included, the sample must contain a minimum of 10 events per variable.¹² In this study, 157 eligible patient medical records were identified, of which there were 52 cases of patients who received sexual health counseling and 76 cases of patients using contraception. Therefore, the 2 logistic regression models for these 2 dependent variables could contain up to 5 and 7 independent variables, respectively. Fewer independent variables entered the final models based on the process described above; therefore, the sample size was considered adequate.

Results

A total of 157 eligible patient medical records were identified. [Table 1](#) describes the demographics and clinical characteristics of these patients. All patients were female, and the mean age was 20.5 years. Of the patients, 70.1% were white/Caucasian, 81.5% were non-Hispanic, and 89.8% were single. The most common type of cancer was hematologic, comprising 40.8% of the patients, followed by thyroid cancer in 31.2%. For treatment, 52.2% underwent surgery, 60.5% received chemotherapy, and 52.2% received radiation.

In all, 91.7% of patients had never been pregnant, and 28.7% did not have sexual activity status documented anywhere in the medical record. Of those who did have documented sexual activity status (71.3% of the total cohort), half

Table 1
Patient Demographics and Clinical Characteristics (n = 157)

	n	%
Age range, y		
15–20	80	51.0
21–25	77	49.0
Race		
Asian	11	7.0
Black or African American	13	8.3
White or Caucasian	110	70.1
Other/not listed	23	14.6
Ethnicity		
Hispanic or Latina	29	18.5
Not Hispanic or Latina	128	81.5
Marital Status		
Single	141	89.8
Married or other	16	10.2
Cancer type		
Breast	9	5.7
Gynecologic	8	5.1
Hematologic	64	40.8
Neurologic	15	9.6
Sarcoma	8	5.1
Thyroid	49	31.2
Other	4	2.5
Treatment		
Surgery	82	52.2
Chemotherapy	95	60.5
Radiation	82	52.2
Bone marrow transplant	8	5.1
Hormone therapy	7	4.5
Targeted/biologic therapy	28	17.8
Prior pregnancy		
Yes	13	8.3
No	144	91.7
Sexually active		
Yes	56	35.7
No	56	35.7
Not documented	45	28.7
Contraception use		
Yes	76	48.4
No	81	51.6
Sexual health counseling		
Yes	52	33.1
No	105	66.9

were sexually active. Of those documented as sexually active, 82.1% had male partners and 7.1% had female partners. The remaining sexually active patients did not have the sex of their partner(s) documented.

Only 33.1% of patients in this study received sexual health counseling. Table 2 shows associations between patient characteristics and documented sexual health counseling based on Pearson χ^2 or Fisher exact tests. Table 3 shows the variables that were found to be statistically significant predictors of having documented sexual health counseling based on multivariate logistic regression. Younger age (age 15–20 years) was significantly associated with a lower likelihood of documented sexual health counseling (OR 0.31, 95% CI 0.14–0.70, $P = .005$), and Hispanic or Latina ethnicity was associated with a greater likelihood (OR 6.07, 95% CI 1.81–20.40, $P = .004$). Having had at least 1 prior pregnancy also had a significant association (OR 4.93, 95% CI 1.31–18.57, $P = .018$).

In all, 48.4% of patients were documented as using a contraceptive method during their cancer treatment. Contraceptive methods used are shown in Figure 1. The most popular method used was combination oral contraceptive pills (COCP), with 24.2% of all patients (50.0% of those using

contraception) using this method. Long-acting reversible contraceptive (LARC) methods, including intrauterine devices (IUD) and implants, were used by 5.7% of all patients (11.8% of those using contraception).

Table 2 shows associations between patient characteristics and any contraception use based on Pearson χ^2 and Fisher exact tests. In all, 69.6% of patients who were sexually active were documented as using contraception. Table 4 shows the variables that were found to be statistically significant predictors of contraception use based on multivariate logistic regression. Sexual activity was significantly associated with contraception use (OR 4.18, 95% CI 1.80–9.68, $P = .001$). Having documented sexual health counseling was associated with more than 3 times the likelihood of using contraception compared to not having documented counseling (OR 3.36, 95% CI 1.35–8.34, $P = .009$). There were no pregnancies or positive pregnancy tests during cancer treatment documented in the medical records of this cohort.

Discussion

The goal of this study was to assess the frequency of sexual health counseling and contraception use among AYA female cancer patients, whether there is an unmet need in this area, and whether certain factors make patients more or less likely to receive these services.

The National Comprehensive Cancer Network (NCCN) notes that reproductive health and contraception should be discussed with AYA patients prior to starting treatment.¹⁴ However, results of this study show that a minority of patients (only 33.1%) have any such counseling documented. This is a larger percentage compared to other retrospective studies looking at different subsets of the AYA cancer population.^{10,11}

Commonly cited barriers to sexual health counseling for AYA cancer patients include limited provider knowledge about contraception, severity of patient illness, the belief that sick patients are not sexually active, time constraints, or the assumption that patients will bring the topic up if needed.^{15–17} This study showed that the younger subset of AYA patients were less likely to be counseled. Potential reasons for this include false assumptions about sexual activity in this age group,¹⁸ a focus on survivorship,¹⁷ parental influence,^{19–21} and patient reluctance to discuss sexual health with their oncology providers.^{3,22}

Approximately half of the patients in this cohort had documentation demonstrating contraception. Of the patients without documented contraception use, although some were not sexually active, many were (including specifically documented as sexually active with men), and many did not have sexual activity status documented. It is likely that there were patients who had unmet contraceptive needs. The most common birth control method in this cohort was COCP, with LARC options being less common, similar to patterns seen in the general population of healthy women^{23,24} and in other cohorts of cancer patients.⁵ It is recommended that adolescents be counseled on the range of reversible contraceptive methods, including LARC, and that all contraceptive options be readily accessible to

Table 2
Frequency of Documented Sexual Health Counseling and Contraception Use Across Patient Characteristics

Characteristic	Documented Sexual Health Counseling		Contraception Use	
	n (%)	P value*	n (%)	P value*
Age, y		.011		.581
15-20 (n = 80)	19 (23.8)		37 (46.3)	
21-25 (n = 77)	33 (42.9)		39 (50.6)	
Race		.070		.778
Asian (n = 11)	1 (9.1)		6 (54.5)	
Black or African American (n = 13)	3 (23.1)		6 (46.2)	
White or Caucasian (n = 110)	36 (32.7)		55 (50.0)	
Other/not specified (n = 23)	12 (52.2)		9 (39.1)	
Ethnicity		.001		.987
Hispanic or Latino (n = 29)	17 (58.6)		14 (48.3)	
Not Hispanic or Latino (n = 128)	35 (27.3)		62 (48.4)	
Marital Status		.340		.508
Married/other (n = 16)	7 (43.8)		9 (56.3)	
Single (n = 141)	45 (31.9)		67 (47.5)	
Cancer Type		.595		.785
Breast (n = 9)	3 (33.3)		4 (44.4)	
Gynecologic (n = 8)	2 (25.0)		5 (62.5)	
Hematologic (n = 64)	21 (32.8)		29 (45.3)	
Neurologic (n = 15)	3 (20.0)		7 (46.7)	
Sarcoma (n = 8)	4 (50.0)		6 (75.0)	
Thyroid (n = 49)	19 (38.8)		23 (46.9)	
Other (n = 4)	0 (0.0)		2 (50.0)	
Surgery		.775		.824
Yes (n = 82)	28 (34.1)		39 (47.6)	
No (n = 75)	24 (32.0)		37 (49.3)	
Chemotherapy		.594		.741
Yes (n = 95)	33 (34.7)		47 (49.5)	
No (n = 62)	19 (30.6)		29 (46.8)	
Radiation		.532		.824
Yes (n = 82)	29 (35.4)		39 (47.6)	
No (n = 75)	23 (30.7)		37 (49.3)	
Bone marrow transplant		.441		1.000
Yes (n = 8)	4 (50.0)		4 (50.0)	
No (n = 149)	48 (32.2)		72 (48.3)	
Hormone therapy		.686		.713
Yes (n = 7)	3 (42.9)		4 (57.1)	
No (n = 150)	49 (32.7)		72 (48.0)	
Targeted/biologic therapy		.314		.852
Yes (n = 28)	7 (25.0)		14 (50.0)	
No (n = 129)	45 (34.9)		62 (48.1)	
Prior pregnancy		.010		.682
Yes (n = 13)	9 (69.2)		7 (53.8)	
No (n = 144)	43 (29.9)		69 (47.9)	
Sexual activity		.327		.000
Yes (n = 56)	23 (41.1)		39 (69.6)	
No (n = 56)	18 (32.1)		20 (35.7)	
Documented sexual health counseling				0.003
Yes (n = 52)	—	—	34 (65.4)	
No (n = 105)	—	—	42 (40.0)	

* Unadjusted comparisons, P values based on Pearson χ^2 and Fisher exact tests.**Table 3**
Predictors of Sexual Health Counseling Based on Multivariate Logistic Regression

Characteristic	OR	95% CI	P Value
Age			
15-20	0.31	0.14-0.70	.005
21-25			
Ethnicity			
Hispanic or Latina	6.07	1.81-20.40	.004
Not Hispanic or Latina			
Prior Pregnancy			
Yes	4.93	1.31-18.57	.018
No			

CI, confidence interval; OR, odd ratio.

them.²⁵ Although the reason for the lower rate is unknown, our findings may demonstrate another unmet need and a possible area for intervention, as LARC options have several benefits in this population including highly effective contraception and, in some cases, reduction of menstrual blood loss.²⁶

In this study, not surprisingly, sexual activity was associated with increased rates of contraception. However, sexual activity was not associated with higher rates of sexual health counseling. Controlling for sexual activity, however, the data did show that documented sexual health counseling was associated with increased rates of contraception use. This is an encouraging finding, showing that counseling is associated with a clinically meaningful

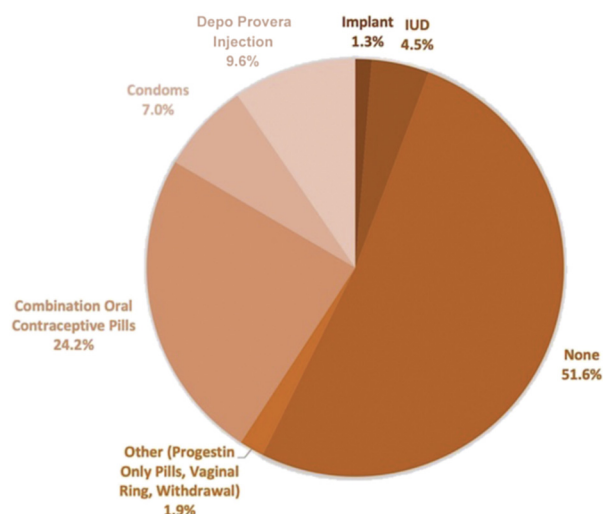


Fig. 1. Contraceptive methods used by patients undergoing cancer treatment ($n = 157$). When a patient was documented as using more than 1 method (simultaneously or sequentially), the most effective type based on World Health Organization tiers of contraceptive effectiveness¹³ is listed. If 2 methods of the same efficacy were used sequentially, the first method used is listed.

benefit. This finding is corroborated by other research, including survey research in AYA cancer patients among whom contraceptive counseling was associated with higher rates of more effective contraception.⁵

The impact of cancer treatment on fertility is more commonly discussed in this population. The potential loss of fertility can be a major source of psychosocial distress for AYA cancer patients; and women of reproductive age with gynecologic malignancies face additional distress, as these diagnoses and their treatment may uniquely affect fertility, sexuality, and identity.^{27,28} Education about options for fertility preservation is key. Embryo and oocyte cryopreservation may be options for women facing potential infertility secondary to treatment for any type of malignancy. Newer methods of fertility-sparing surgery now exist for certain gynecologic malignancies, and oophorectomy may be an option to shield reproductive organs from radiation therapy.^{6,29}

Discussions of fertility are critically important for their own sake, but also as they relate to other aspects of sexual health. Conversations about fertility preservation may lead AYA patients to develop incorrect beliefs about their fertility and underestimate their risk of pregnancy.³⁰ Studies have shown that young adult female cancer survivors were significantly more likely to have unintended pregnancies compared to the general population, to have pregnancies

ending in medical abortions compared to healthy age-matched siblings, and to use emergency contraception more than the general population.^{31–33} Of those survivors with a history of chemotherapy, having the perception of infertility is predictive of contraception nonuse, even without clinical evidence of infertility.³⁴ As such, discussions about fertility preservation provide an ideal opportunity to provide education about the continued need for contraception.

This study had several strengths. Although there is an existing body of literature examining the intersection between gynecology and adolescent and young adult oncology as it relates to infertility and fertility preservation, little is known about sexual health counseling and contraception use in this population. This study adds to the existing limited body of literature by examining a population with a wide age range and diversity in cancer type. Importantly, our study identifies characteristics of patients who are less likely to receive sexual health counseling and less likely to use contraception. This, in turn, identifies potential opportunities for intervention.

There are several limitations of this study. As a retrospective chart review, these data are based on documentation, which may not always be accurate. It is possible that some patients received counseling, but those conversations were not documented. Documentation of contraception prescriptions do not necessarily translate into contraception use, and rates of condom use may have been underestimated. Sexual activity status was often missing from the medical record, and it is possible that the documented information was sometimes inaccurate, as sexual activity can change over time. Despite these limitations, it is important to highlight what is and is not documented; as such, this study is informative about the current landscape of sexual health care for female AYA patients undergoing cancer treatment.

In conclusion, this study showed that a majority of AYA female patients undergoing cancer treatment did not have documented sexual health counseling, and that many did not have documentation indicating contraception use. However, patients who received counseling were more likely to use contraception. There appears to be a need for increased rates of sexual health counseling in female AYA cancer patients. Efforts should be made to explore and to overcome current barriers, especially for the younger, adolescent patients, who may represent an especially vulnerable subset of this population. Addressing the major barriers that limit the provision of sexual health care in the oncology context may optimize comprehensive care for these patients.

Table 4
Predictors of Contraception Use Based on Multivariate Logistic Regression

Characteristic	OR	95% CI	P Value
Sexual activity			
Yes	4.18	1.80-9.68	.001
No			
Received Sexual health Counseling			
Yes	3.36	1.35-8.34	.009
No			

CI, confidence interval; OR, odd ratio.

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