



Perceptions of Infertility and Reproductive Concerns in Adolescent and Young Adult Female Cancer Survivors

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This cross-sectional survey study explores the fertility perceptions of adolescent and young adult female cancer survivors ($n=111$) and relationships to fertility counseling and reproductive distress. Satisfaction with post-treatment fertility counseling ($\beta=-0.20$, $p=0.04$), perceived consequences of cancer-related fertility changes ($\beta=0.26$, $p=0.03$), and understanding of one's reproductive health ($\beta=-0.22$, $p=0.03$) correlated with reproductive distress, controlling for covariates ($F(10, 88)=3.50$, $p<0.001$). Findings suggest that post-treatment counseling may be important to addressing survivors' perceptions of fertility and reproductive potential, which influences levels of distress and to create a greater sense of control on their road to parenthood.

Keywords: illness perceptions, reproductive concerns, fertility, infertility, cancer survivorship, counseling

Introduction

FERTILITY IS AN important quality of life issue for adolescent and young adult female (AYA-F) cancer survivors who hope to have a child in the future.¹ Gonadotoxic treatments can impact fertility and limit family-building options. Estimates of gonadotoxic treatment effects vary widely based on the cancer type, treatment, age of treatment, pre-existing reproductive health, and nulliparous status.²⁻⁴

Treatments can lead to premature ovarian insufficiency or diminished ovarian reserve, which has implications for one's reproductive window and likelihood of success with reproductive medicine.⁵ AYA-Fs experience frequent worries, anxiety, and depression related to their fertility in post-treatment survivorship.⁶ By learning more about AYA-Fs' perceptions of their fertility after cancer, we can better support AYA-Fs in managing their concerns and distress.

The Self-Regulation Model (SRM) is a commonly used framework to explore people's reactions to (risk of) illness. It posits that an individual will react to a health threat through two simultaneous responses—cognitive and emotional—that influence coping strategies.^{7,8} These dual responses are called illness perceptions and determine the perceived threat.

Coping strategies are critical to managing emotions and assessing the illness' overall threat.⁸

The SRM describes five types of illness perceptions: *identity* (label and symptoms), *timeline* (chronic/acute), *consequences*, *causes*, and *controllability*.^{8,9} Further work divided *control* into *self-control*, *treatment-control*, *illness coherence*, and *emotional representations*.¹⁰ In this study, we define fertility perceptions as encompassing AYA-Fs' beliefs about cancer-related changes to reproductive health, including confirmed infertility, threat of lowered reproductive potential (e.g., reduced ovarian reserve), or altered reproductive viability (e.g., loss of reproductive organ or inability to safely carry a pregnancy).

Illness perceptions strongly correlate with physical and social functioning, psychological well-being, coping, and treatment decisions in numerous chronic illness contexts.^{11,12} The SRM framework has been applied to the experience of infertility and its treatment.¹³⁻¹⁵ Greater perceived *consequences* of infertility has the strongest association with greater distress and lower well-being, whereas greater *illness coherence* of infertility relates to lower distress and better quality of life.^{10,11,15}

This cross-sectional study aimed to (1) describe AYA-F survivors' perceptions of cancer-related changes to

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reproductive health, that is, fertility perceptions, (2) evaluate associations between post-treatment fertility counseling and types of fertility perceptions, and (3) evaluate associations between fertility perceptions and reproductive distress.

Methods

These secondary analyses were part of a larger study examining AYA-Fs' fertility and family-building experiences after cancer.¹ Study procedures were approved by the Northwell Health Institutional Review Board (#18-0516).

Participants

Eligibility criteria included (1) assigned female at birth, (2) aged 15–45 years, (3) cancer history and completion of gonadotoxic treatment (e.g., systemic chemotherapy, surgery affected reproductive organs, and/or pelvic radiation or radiation to the brain), (4) had not had a child since their cancer diagnosis, and (5) reported parenthood desires or undecided family-building plans. Participants could have been on long-term adjuvant or endocrine, or currently pregnant (or surrogate pregnant).

Procedure

Recruitment identified eligible patients through electronic medical records and social media partnerships with young adult cancer organizations (e.g., Stupid Cancer, Cactus Cancer Society, and The Samfund). Eligibility was confirmed through phone and informed consent completed. Parental consent and participant assent were obtained for minors. After enrollment, participants completed an online survey through REDCap (Research Electronic Data Capture), a secure Health Insurance Portability and Accountability Act-compliant electronic data capture tool.

Measures

A standard questionnaire collected sociodemographic and medical information. An investigator-designed question measured satisfaction with provider conversations about fertility in *post-treatment survivorship*, that is, “Has your oncologist or other health care professional discussed fertility with you during your follow-up care?” Response options were (1) Yes, I have been satisfied with the amount of information and counseling I received; (2) Yes, but I have NOT been satisfied with the amount of information and counseling I received and still have questions; (3) No, it has not been discussed at all, but I wish it was; (4) No, I have not been interested in receiving this information, or it is not applicable; and (5) I do not remember or am unsure.

Illness perceptions. Illness perceptions were measured by the Illness Perception Questionnaire-Revised (IPQ-R), adapted for cancer-related reproductive health changes.¹⁰ We used five subscales: (1) *consequences* represents the impact of fertility on one's life (six items, e.g., “My fertility has major consequences on my life”); (2) *personal control* represents one's perceived control over fertility (six items, e.g., “There is a lot which I can do to control problems related to my fertility”); (3) *treatment control* represents belief that treatments can control one's fertility (six items, e.g., “There are treatments that can address any fertility problems that I

might experience”); (4) *illness coherence* represents understanding of fertility (five items, e.g., “My fertility is a mystery to me”); and (5) *emotional representations* measures one's affective responses to fertility (six items, e.g., “My fertility makes me angry”).

Responses were on a 5-point scale (1 = strongly disagree to 5 = strongly agree). Higher scores on the *consequences* subscale represent a belief that cancer-related fertility changes have had a more severe impact on their lives (negative outcome). Higher scores on the *personal control* and *treatment control* subscales represent greater perceived controllability of potential fertility problems (positive outcomes). Higher scores on the *illness coherence* subscales represent greater personal understanding of their fertility (positive outcome). Higher scores on the *emotional representations* subscale represent stronger negative feelings about their fertility (negative outcome).

Reproductive distress. Reproductive distress was measured by the Reproductive Concerns After Cancer Scale (RCACS; 18 items), which includes six domains: fertility potential, becoming pregnant, personal health, child's health, partner disclosure, and acceptance.¹⁶ Responses are on a 5-point scale (1 = strongly disagree to 5 = strongly agree). RCACS mean scores range from 18 to 90. Higher scores indicate higher levels of distress.

Data analysis

Descriptive statistics described fertility perceptions (IPQ-R subscales). *T*-tests and Pearson correlations evaluated bivariate relationships among study variables. A linear regression model was specified with fertility counseling and fertility perceptions as independent variables, and reproductive distress as the dependent variable. A set of *a priori* covariates (i.e., age, age at cancer diagnosis, race, ethnicity, education level, and household income) was entered in Step 1. Satisfaction with post-treatment fertility counseling (dichotomized) was entered in Step 2. The IPQ-R subscales were entered in Step 3. The emotional representations subscale was not included due to high correlation with reproductive distress.

Results

AYA-Fs ($n = 111$) averaged 31.0 years old (standard deviation = 5.49) and were a median 3-years post-treatment (Table 1). Most (76%) identified as White and 18% were Hispanic/Latina. Most were nulliparous (90%) and unsure of their desired reproductive timeline (82%). Most (78%) reported that a provider discussed fertility with them before treatment, 35% met with a fertility specialist, and 16% underwent fertility preservation before treatment.

The majority ($n = 70$; 63%) of AYA-Fs had post-treatment fertility discussions with their provider; however, only 27% ($n = 30$) were satisfied with discussions, whereas 36% ($n = 40$) were not satisfied with the amount of information and counseling they received and still had questions. AYA-Fs who did not have post-treatment discussions included those who wished they had ($n = 28$; 25%) and those who were not interested or did not remember ($n = 13$; 12%).

Mean scores and representative items for IPQ-R subscales are listed in Table 2. Based on representative subscale items, a minority (32%) of AYA-Fs reported having a clear

TABLE 1. SOCIODEMOGRAPHIC AND MEDICAL CHARACTERISTICS OF THE SAMPLE (n=111)

	Mean (SD)	Range
Sociodemographic information		
Age (years) ^a	30.98 (5.49)	16–42
Age at diagnosis (years)	24.04 (25.50)	1–38
	n	%
Race		
White	84	75.7
Black	6	5.4
Asian or Pacific Islander	4	3.6
Other	5	4.5
More than one race	8	7.2
Unknown/prefer not to answer	4	3.6
Ethnicity		
Hispanic/Latina	20	18.0
Non-Hispanic/Latina	90	81.1
Unknown/prefer not to answer	1	0.9
Highest education		
High school	14	12.6
Vocational training, other than high school	5	4.5
College	52	46.8
Postgraduate	40	36.0
Student status		
Full or part time	19	17.1
Not enrolled in school	92	82.9
Employment status		
Employed full time	68	61.3
Employed part time	25	22.5
Not employed	18	16.2
Household income		
<\$50,000	38	34.2
\$50,000–\$100,000	34	30.6
>\$100,000	24	21.6
Unknown/prefer not to answer	15	13.5
Locality		
Urban	39	35.1
Suburban	63	56.8
Rural	6	5.4
Prefer not to answer	3	2.7
Nulliparous	100	90.1
Clinical information		
Cancer type ^b		
Lymphoma	29	25.1
Leukemia	27	24.3
Breast	24	21.6
Cervical, ovarian, uterine, or endometrial	16	14.4
Colon or rectal	8	7.2
Sarcoma	6	5.4
Other	10	9.0
Treatment with potential impact on fertility ^b		
Surgery that affected uterus and/or ovaries	18	16.2
Radiation therapy that included the abdominal or pelvic region or brain	25	22.5
Chemotherapy	99	89.2
Bone marrow or stem cell transplant	17	15.3

(continued)

TABLE 1. (CONTINUED)

	n	%
Immunotherapy	3	2.7
Hormone therapy	17	15.3
Fertility-related information		
Underwent fertility preservation before cancer treatment ^{b,c}	18	16.2
Had a fertility evaluation since completing cancer treatment	42	37.8
Been told that you will not be able to get pregnant or carry a pregnancy		
Yes	30	27
No	73	65.8
I do not remember	6	5.4
Prefer not to answer	1	0.9

^aAge categories included adolescents, 15–17 years old (n=2, 1.8%), emerging adults, 18–29 years old (n=40, 36.0%), young adults, 30–39 years old (n=63, 56.8%), and adults, 40–45 years old (n=6, 5.4%).

^bCategories are not mutually exclusive.

^cFertility preservation included egg freezing (n=10, 9.0%), embryo freezing (n=6, 5.4%), ovarian tissue cryopreservation (n=1, .9%), and other (n=4, 3.6%).

SD, standard deviation.

understanding of their fertility and problems they might have in the future, yet 68% believed (potential) problems related to their fertility have major consequences on their lives. Only 11% of AYA-Fs endorsed a sense that they have strong personal control over problems related to their fertility, although 35% endorsed a sense of control over improving their fertility or reproductive health. The majority (65%) endorsed strong negative emotional representations related to fertility.

There were no differences in any of the IPQ subscales based on fertility preservation history (all *ps* > 0.05) with the exception of the consequences subscale (*p* = 0.04), suggesting that women who underwent fertility preservation believed that cancer-related changes to fertility had a greater impact on their life.

Those who had a *pre*-treatment fertility discussion with a provider reported higher scores on the IPQ treatment control subscale compared with those who had not had a discussion, *t*(109) = -2.01, *p* = 0.047). There was no difference in levels of reproductive distress based on the occurrence of *pre*-treatment fertility discussions (*t*[106] = 0.19, *p* = 0.81).

Thus, findings suggest that *pre*-treatment counseling may lead to survivors feeling a greater sense of control over their future fertility and treatment, but this does not translate to lower levels of reproductive distress *post*-treatment. There was also no difference in levels of reproductive distress based on menstruation status (*F*[4,103] = 1.99, *p* = 0.10), nulliparity (*t*[106] = -0.51, *p* = 0.61), or fertility preservation history (*t*[61] = 0.20, *p* = 0.84).

In a two-group comparison between those who were satisfied with *post*-treatment fertility discussions versus all others (i.e., did not have discussions or had them but were unsatisfied), AYA-Fs who were satisfied with discussions endorsed more positive emotional representations of their fertility (*t*[109] = 3.40, *p* < 0.001) and greater perceived treatment control (*t*[109] = -3.08, *p* = 0.003). Satisfaction with

TABLE 2. DESCRIPTIVE STATISTICS OF THE ILLNESS PERCEPTIONS QUESTIONNAIRE-REVISED

Descriptive statistics of illness perceptions—adapted to refer to cancer-related infertility risks

IPQ-R subscale	Median	Mean ± SD	Range	Sample item	% agree or strongly agree
Illness coherence	12	12.8 ± 4.2	4–20	“I don’t understand my fertility or the problems that I might have now or in the future.”	31.4
Consequences	17	17.1 ± 4.2	5–25	“My fertility and (potential) problems have major consequences on my life.”	67.5
Personal control	15	15.3 ± 3.3	10–26	“There is a lot which I can do to control problems related to my fertility.”	10.8
Treatment control	18	16.5 ± 5.2	6–29	“There is very little that can be done to improve my fertility or reproductive health.”	49.5
Emotional representation	22	21.5 ± 6.1	6–30	“When I think about my fertility I get upset.”	64.8

IPQ-R, Illness Perception Questionnaire-Revised.

post-treatment fertility discussions did not correlate with IPQ-R subscales of illness coherence, consequences, or personal control.

In bivariate analysis, higher levels of reproductive distress related to a lower understanding of fertility and treatment-related infertility risks (IPQ-R illness coherence, $r = -0.25$, $p = 0.01$), a stronger belief that cancer-related fertility changes caused a more severe impact on their lives (IPQ-R consequences, $r = 0.26$, $p = 0.006$), and lower likelihood of believing (potential) fertility problems could be treated (IPQ-R treatment control, $r = -0.21$, $p = 0.03$). Not surprisingly, higher levels of reproductive distress related to more negative emotions surrounding fertility (IPQ-R emotional representation, $r = 0.56$, $p < 0.001$). Reproductive distress was not related to one’s perceived control over their fertility (IPQ personal control, $r = -0.14$, $p = 0.16$).

Fertility counseling and perceptions as correlates of reproductive distress

A stepwise linear regression identified relationships between fertility counseling and fertility perceptions on rep-

roductive distress (Table 3). The overall model was significant ($F[10, 88] = 3.50$, $p < 0.001$), accounting for 29% of the variance in reproductive distress. Satisfaction with post-treatment fertility counseling correlated with lower levels of reproductive distress ($\beta = -0.20$, $p = 0.04$). With respect to fertility perceptions, greater perceived consequences (IPQ-R consequences, $\beta = 0.26$, $p = 0.03$) and lower understanding of one’s fertility (IPQ-R illness coherence, $\beta = -0.22$, $p = 0.03$) correlated with higher levels of reproductive distress. Among covariates, age negatively correlated with reproductive distress ($\beta = -0.28$, $p = 0.04$).

Discussion

This study examined AYA-F cancer survivors’ perceptions of and emotions surrounding cancer-related changes to their fertility. About a third (31%) of survivors lacked a clear understanding of their fertility post-treatment and (potential) future problems, yet most (68%) perceived the consequences of cancer-related fertility changes as serious, and an even greater majority (65%) endorsed negative emotional representations of their fertility. Only a small proportion of

TABLE 3. REGRESSION MODELS EVALUATING FERTILITY COUNSELING AND ILLNESS PERCEPTIONS AS CORRELATES OF REPRODUCTIVE DISTRESS

DV: reproductive distress (RCACS) $F(10,88) = 3.50$, $p < 0.001$

Step	Variable ^a	R ²	R ² Δ	Sig. F Δ	B	SE	β	p
1	Constant	0.12	0.08	0.03	69.42	7.98		
	Age (years)				-0.54	0.25	-0.28	0.04
	Age at diagnosis (years)				0.33	0.16	0.26	0.04
	Race (0 = White)				-1.05	2.67	-0.04	0.70
	Ethnicity (0 = non-Hispanic/Latina)				3.61	2.93	0.13	0.22
	Employment status (0 = unemployed)				-2.32	2.76	-0.08	0.40
2	Satisfaction with post-treatment fertility counseling (0 = not satisfied)	0.20	0.08	0.003	-4.79	2.26	-0.20	0.04
	Consequences	0.29	0.09	0.04	0.57	0.26	0.26	0.03
Personal control	-0.16				0.27	-0.08	0.56	
Treatment control	0.02				0.27	0.01	0.93	
Illness coherence	-0.42				0.19	-0.22	0.03	

^aA *priori* covariates included age, race (two groups: White vs. all other racial groups), ethnicity (non-Hispanic/Latina vs. Hispanic/Latina), education (high school/vocational vs. college/graduate), and employment (not employed vs. full/part-time employed). The IPQ-R Emotional Representations subscale was excluded due to concerns about multicollinearity with reproductive distress (RCACS). DV, dependent variable; RCACS, Reproductive Concerns After Cancer Scale; SE, standard error.

survivors (11%) endorsed a sense of strong personal control over their fertility, although half (50%) reported a sense of control over treatments.

Consistent with prior work,^{13,15,17,18} lower understanding of one's fertility and greater perceived consequences were associated with higher levels of reproductive distress. Results provide quantitative data that are consistent with our qualitative findings of AYA-Fs' cognitive and emotional reactions to cancer-related fertility changes.¹ Fertility perceptions may be modifiable targets of intervention to alleviate AYA-Fs' distress and support coping behaviors.

Findings suggest that fertility counseling in post-treatment survivorship may attenuate negative fertility perceptions. Although only 27% of survivors were satisfied with the information and counseling received post-treatment, this subgroup endorsed greater perceived control over infertility treatments and more positive emotional representations of their fertility.

Interestingly, 37% of participants underwent a fertility evaluation, yet more than two-thirds believed they would have fertility issues. Subjective perceptions of reproductive health may be influenced by many factors, including socioeconomic status, mental health history, sociocultural background, prior experiences, or peer stories.^{11,19–21} Survivors may seek out informal informational resources such as social media, peers, and “Googling,” and develop misconceptions or unwarranted fears.

Thus, in addition to *pre*-treatment oncofertility counseling, follow-up counseling in *post*-treatment survivorship is also needed, although often lacking.^{22,23} At diagnosis, conversations focus on gonadotoxic treatment risks and options to preserve fertility. After treatment is completed, conversations may include options to evaluate and monitor fertility, consider post-treatment fertility preservation if appropriate, options for future family building, and to make referrals as needed. Conversations may also include values clarification, timeline considerations, navigating decision-making, and preparing for potential barriers (e.g., high cost). Ongoing check-ins signal to patients that providers may be a trusted resource if and when they are ready to discuss it.

Limitations include the cross-sectional design, lack of diversity, and participants representing higher socioeconomic status. We were limited in our assessment of factors related to fertility perceptions such as pre-existing gynecological issues. Fertility perceptions may change over time and differ based on racial/ethnic or cultural values. This was a nationwide self-report survey study and we were unable to obtain medical data. In addition, satisfaction with provider communication was assessed with a single item. Future studies should explore these relationships longitudinally with diverse populations of survivors and should explore facilitators and barriers to patient–provider oncofertility discussions.

Illness perceptions are a modifiable factor to address post-treatment. Learning how this population perceives risk and experiences cancer-related fertility changes can improve how we support AYA-Fs in managing their concerns and family-building goals.

Authors' Contributions

Conceptualization, methodology, formal analysis, and investigation by C.B. and A.Z.; writing original draft prep-

aration by C.B., A.Z., and A.M.D.; writing—review and editing by J.S.F., M.D., and L.S.; funding acquisition by C.B., J.S.F., and M.D.

Ethical Approval

Study procedures were approved by the Northwell Health Institutional Review Board.

Consent to Participate

Informed consent was obtained from all participants included in the study. Parental consent and participant assent were obtained for minors.

Disclaimer

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Author Disclosure Statement

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