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Greater fertility distress and avoidance relate to poorer decision making about family building after cancer among adolescent and young adult female survivors

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Abstract

Background: Many adolescent and young adult female (AYA-F) cancer survivors face decisions about family building using reproductive medicine or adoption to achieve parenthood. This study evaluated associations among reproductive distress, avoidance, and family-building decision making and identified sociodemographic and clinical characteristics related to high distress and avoidance.

Methods: A cross-sectional survey assessed AYA-F survivors' oncofertility experiences. Measures included an investigator-designed Unmet Information Needs scale, Reproductive Concerns After Cancer Scale, Impact of Events Scale—Avoidance subscale, Decision Self-Efficacy scale, and Decision Conflict Scale. Two linear regression models evaluated correlates of decision self-efficacy and decisional conflict about family building after cancer. Bivariate analyses evaluated correlates of avoidance using Pearson's correlation, *t*-test, and ANOVA.

Results: AYA-Fs ($N = 111$) averaged 31-years-old ($SD = 5.49$) and 3 years post-treatment (range: 1–23 years); 90% were nulliparous. Most common diagnoses were leukemia (24%) and breast cancer (22%). Average decisional conflict was 52.12 ($SD = 23.87$, range: 0–100); 74% of the sample reported DCS scores within the clinically significant range. Higher levels of reproductive distress ($B = -0.23$, $p = 0.04$) and avoidance ($B = -0.24$, $p = 0.02$) related to lower decision self-efficacy. Younger age ($B = -0.18$, $p = 0.03$), greater unmet information needs ($B = 0.33$, $p < 0.001$), and higher levels of reproductive distress ($B = 0.34$, $p = 0.001$) related to worse decisional conflict. Predictors of distress and avoidance were identified.

Conclusions: After cancer treatment, high fertility distress and avoidant coping were associated with poorer quality decision making about family building after cancer. Fertility counseling post-treatment should support self-efficacy and constructive coping skills to counteract high distress, maladaptive coping, and facilitate values-based decision making.

KEYWORDS

adolescent and young adult cancer, decision making, fertility, infertility, oncofertility, reproductive distress

1 | INTRODUCTION

Gonadotoxic cancer treatments can lead to infertility and/or greater difficulty achieving parenthood via reproductive medicine or adoption.[1] Adolescent and young adult female (AYA-F) cancer survivors report high rates of unmet fertility-related needs in both the pre- and post-treatment time periods, and gaps in clinical care.[2] Survivors are often distressed and uncertain about reproductive potential and family-building options, timing to pursue family building, and its financial obligations.[3,4] Reproductive concerns in post-treatment survivorship are associated with increased depressive symptoms and lower quality of life.[5,6] There is an urgent need to better support women who are concerned about their fertility and family building after cancer treatment to guide patient-centered care and referral to medical and supportive care resources.

We previously described the decision-making processes of AYA-Fs considering family-building options after cancer.[7] When prompted to think about fertility and family building in qualitative interviews, most survivors reported multiple areas of uncertainty (e.g., fertility status and childbearing potential, reproductive timeline, and likelihood of success) and a range of negative emotions (e.g., distress, anger, fear).[7] AYA-Fs described various coping mechanisms to manage fertility-related distress.[7] Some reported problem-solving behaviors, self-advocacy, and playing an active role in addressing fertility-related needs, while others reported postponement and avoidance to manage negative feelings.[7] After a stressful or traumatic event, avoidance of thoughts, feelings, and reminders of the trauma is a common reaction, and part of the symptomatology of post-traumatic stress disorder. Cancer is well recognized as a trauma that can lead to post-traumatic stress, and up to 44% of AYAs with cancer report post-traumatic stress symptoms at 12 months post-diagnosis.[8] Post-cancer infertility has been described as being as traumatic as the cancer diagnosis (‘dual trauma’).[9] Within oncofertility, for women who are at risk for premature ovarian failure, postponement and avoidance of fertility care may cause them to miss their narrowed reproductive window to have a biologically related child if desired. Postponement and avoidance may also mean they miss the opportunity to prepare for future barriers associated with reproductive medicine and adoption such as planning for financial costs or legal and logistical complications.

The purpose of the present study was to characterize the oncofertility experiences of AYA-Fs who completed gonadotoxic treatment and desired a child in the future. Specifically, we aimed to describe reproductive distress and avoidant coping exhibited by women and evaluate associations with decision-making processes about family building after cancer. Prior systematic reviews have focused on reproductive concerns and fertility-related distress among adolescent and young adult cancer survivors.[2,10] Building on this, and based in our prior qualitative work,[7,11] we sought to contribute to the empirical understanding of distress and avoidance in response to oncofertility stressors and the impact on decision-making processes about pursuing parenthood. A second aim of the study was to identify who is more likely to report high distress and engage in avoidant coping, which may inform supportive care services to ensure survivors are connected to resources if and when they are needed.

2 | METHODS

These analyses were part of a larger mixed methods study examining AYA-Fs' oncofertility experiences after cancer.[7] The data presented here are the main findings from the cross-sectional quantitative survey, conducted from 2018 to 2019. Study procedures were approved by the Northwell Health Institutional Review Board (#18–0516).

2.1 | Participants

Eligibility criteria included: (1) assigned female at birth, (2) currently aged 15–45 years old, (3) cancer history (at least one diagnosis of malignancy) and completion of gonadotoxic treatment (i.e., systemic chemotherapy, surgery affecting reproductive organs, and/or radiation to the pelvic area or brain), (4) had not had a child since cancer diagnosis (via pregnancy, surrogacy, or adoption), and (5) self-reported parenthood desires or undecided family-building plans (assessed during eligibility review and study enrollment process). The National Cancer Institute defines AYAs as aged between 15 and 39 years,[12] but this was expanded to include women in their 40s who may still be interested in family building. AYA-Fs could have been on long-term adjuvant or endocrine treatment and could have had a child (or children) prior to cancer; two participants were currently pregnant (or a surrogate was pregnant).

2.2 | Procedure

Hospital-based recruitment identified patients through electronic medical records. Study advertisements were posted on patient organizations' social media pages (e.g., Stupid Cancer, Cactus Cancer) with a link to provide contact information using a HIPPA-compliant platform. Follow-up calls confirmed eligibility and completed informed consent and enrollment. Participants were emailed a link to sign the informed consent document via REDCap (Research Electronic Data Capture), a secure, HIPPA-compliant, web-based software platform designed to support data collection hosted at Stanford Center for Clinical Informatics.[13,14] Parental consent and participant assent were obtained for minors. Following enrollment, participants were emailed a link to complete a survey online via REDCap.

2.3 | Measures

All data collected were self-report. Standard questionnaires collected socio-demographic and medical information. Fertility-related questions were developed by study investigators based on clinical experience and our prior research[15] including fertility preservation history, provider discussions, and perceptions of fertility status.

Unmet information needs about fertility and family building were assessed with an investigator-designed measure. The unmet information needs (UIN) scale included five items that asked respondents whether they had as much information as they want about risk of infertility after cancer, risk of premature menopause, options to assess fertility status, options to undergoing fertility preservation post-treatment (if possible), and alternative options for family building after cancer. Responses were yes (0) or no (1), with score ranges from 0 to 5. Higher scores indicated greater unmet information needs. We have used this measure in prior studies[6,15,16] and it demonstrated good internal consistency (Cronbach's alpha = 0.76).

Reproductive distress was measured using 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.[17] Responses are on a 5-point Likert scale from “1 = strongly disagree” to “5 = strongly agree.” RCACS mean scores range from 18 to 90 with higher scores indicating higher levels of distress. The scale demonstrated good internal consistency (Cronbach's alpha = 0.77).

Avoidance of oncofertility-related stress was measured using the Impact of Events Scale—Revised Avoidance (IESR-A) subscale (8 items), developed to measure the subjective response to a traumatic event.[18] Avoidance is one way of responding, characterized by numbing of responsiveness and avoidance of feelings, situations, and ideas. Items ask respondents to rate how they deal with fertility-related stressors and how distressing each difficulty has been on a 5-point Likert scale from “0 = not at all” to “4 = extremely.” An average score was calculated with a possible range of 0 to 4. Higher scores suggest greater avoidance as part of a posttraumatic stress response. The scale demonstrated good internal consistency (Cronbach's alpha = 0.84).

Decision making was measured using two scales. The Decisional Conflict Scale (DCS; 16 items) assesses personal uncertainty in making health decisions and includes five domains: feeling uncertain, feeling uninformed, feeling unclear about values, feeling unsupported, and ineffective decision making.[19,20] The Decision Self-Efficacy scale (DSE; 11 items) measures self-confidence or belief in one's abilities in decision making (e.g., ability to seek and obtain information about options, express concerns and views, and make an informed choice).[21] For both, items were adapted to refer to family-building decisions after cancer, and total scores ranged from 0 to 100. Higher scores on the DCS indicate greater decisional conflict, whereas higher scores on the DSE indicate greater decision self-efficacy. Both scales demonstrated very good internal consistency (DSE Cronbach's alpha = 0.94; DCS Cronbach's alpha = 0.95).

2.4 | Data analysis

Descriptive statistics characterized the sample and outcomes. Two step-wise linear regression models evaluated correlates of decision self-efficacy (model 1) and decisional conflict (model 2) with unmet information needs, reproductive distress, and avoidance as independent variables. Both models included a priori covariates of age, years since treatment, nulliparity (yes/no), and post-treatment fertility evaluation (yes/no). To further explore who may be at risk for high reproductive distress and avoidance, bivariate analyses evaluated relationships between the RCACS and IES-A and other variables using Pearson's correlation, *t*-test, and ANOVA.

3 | RESULTS

3.1 | Descriptive analyses

AYA-Fs (*N* = 111) were on average 30.98 years old (SD = 5.49; range 15–45) and a median 3-years post-treatment (*M* = 6.12, SD = 5.63, range: 1–23 years). Most (76%) identified as White and 18% were Hispanic/Latina. Most AYA-Fs did not have a child (90%) and were unsure of their desired reproductive timeline (82%). Sociodemographic and medical information provided in Table 1.

Before treatment, 78% of AYA-Fs remembered having a fertility discussion with a provider and 16% (*n* = 18) underwent fertility preservation. After treatment, only 15%–31% reported satisfactory discussions about fertility/family-building topics as a part of survivorship care, and 38% had a fertility evaluation post-treatment. A majority of participants (58%–71%) indicated that they did not have enough information about fertility/family-building topics, that is, risk of infertility, risk of early menopause, options to evaluate current fertility status, options to consider fertility preservation after treatment if possible, and alternative family-building options such as in vitro fertilization (IVF), surrogacy, and adoption. Fertility-related clinical experiences and unmet information needs are described in Table 2.

3.2 | Reproductive distress

High levels of reproductive concerns (RCACS *M* = 60.35, SD = 10.56, range: 35–86) were reported. The two areas of greatest concern were related to fertility potential and worrying about the health of a future child. For example, 67% agreed or strongly agreed that they were afraid of being unable to have (more) children, and 63% agreed or strongly agreed that they were worried about passing on a genetic risk for cancer to their children.

3.3 | Avoidant response to oncofertility stressors

There appeared to be a moderate level of an avoidant stress response in reaction to cancer-related infertility risks (*M* = 1.61, SD = 0.88, range: 0–3.75). Across IES-A items, between 8% and 40% reported high avoidance (i.e., answering ‘quite a bit’ or ‘extremely’); 67% reported high avoidance on at least one item. See Figure 1 for all IES-A items.

TABLE 1 Sociodemographic and medical characteristics of the sample ($N = 111$).

Sociodemographic information	Mean (SD)	Range
Age (years)	30.98 (5.49)	16–42
Age at diagnosis (years)	24.04 (8.10)	1–38
Mean time since cancer treatment (years)	6.12 (5.63)	1–23
	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 or vocational training	19	17.1
College	52	46.8
Post-graduate	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		
Less than $50,000	38	34.2
$50,000 - $100,000	34	30.6
Greater than $100,0000	24	21.6
Unknown or prefer not to answer	15	13.5
Nulliparous	100	90.1
Clinical information		
Cancer type[a]		
Lymphoma	29	25.1
Leukemia	27	24.3
Breast	24	21.6
Cervical, ovarian, uterine, or endometrial	17	15.3
Colon or rectal	8	7.2
Sarcoma	6	5.4
Other[b]	9	8.0

TABLE 1 (Continued)

	n	%
Treatment with potential impact on fertility[a]		
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
Immunotherapy	3	2.7
Hormone therapy	17	15.3
Fertility-related information		
Underwent fertility preservation before cancer treatment[a]	18	16.2
Egg freezing	10	9.0%
Embryo freezing	6	5.4%
Ovarian tissue cryopreservation	1	0.9%
Other	4	3.6%
Had a fertility evaluation post-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 don't remember	6	5.4
Prefer not to answer	1	0.9

Abbreviation: SD, standard deviation.

[a] Categories not mutually exclusive.

[b] Other includes brain cancer ($n = 2$), Wilms tumor ($n = 2$), thyroid cancer ($n = 1$), cholangiocarcinoma ($n = 1$), thymoma (thymic carcinoma, $n = 1$), primary central nervous system (PNET) tumor ($n = 1$), myelodysplastic syndrome ($n = 1$).

3.4 | Decision making about future family building

The mean level of decision self-efficacy about family building was 70.50 (SD = 22.91; possible range 0–100). Across items, most AYA-Fs indicated some degree of confidence that they could get the information they needed about fertility and family building, express concerns, ask for advice, handle unwanted pressure from others, figure out the choice that best suited them, let the clinic team know, and delay their decision if needed (scoring 3 or 4 on a 4-point scale from 0-not at all confident to 4-very confident). Conversely, across items, between 30% and 44% reported lower confidence in these areas (scoring 0–2 on a 4-point scale from 0-not at all confident to 4-very confident). For example, 35% indicated low confidence that they could understand the information enough to be able to make a choice about their fertility/family building.

Average decisional conflict was 52.12 (SD = 23.87; possible range of 0–100). This DCS mean was well above the validated cut-off score

TABLE 2 Post-treatment fertility-related clinical experiences and unmet information needs (UIN).

Provider discussions	Yes, satisfied with the amount of information/ counseling received. *n* (%)	Yes, but not satisfied with the amount of information/counseling received and still have questions. *n* (%)	No, it has not been discussed at all, but I wish it was. *n* (%)	No, not interested, does not apply, or I don't remember. *n* (%)
"Since completing your cancer treatment, has your oncologist or other health care professional discussed…"				
Your fertility with you during your follow-up care	30 (27%)	40 (36%)	28 (25.2%)	13 (11.7%)
Risk of infertility or premature menopause	34 (30.6%)	43 (38.7%)	21 (18.9%)	13 (11.7%)
Fertility preservation or alternative family-building options (such as adoption)	17 (15.3%)	18 (16.2%)	56 (50.5%)	20 (18%)

Unmet information needs	% No
"Do you have as much information as you want about…?"	
Risk of infertility	58%
Risk of early menopause	59%
Options to evaluate current fertility status	63%
Options to consider fertility preservation after treatment if possible	60%
Alternative family-building options such as IVF, surrogacy, and adoption	71%

of 37.5 indicating clinically significant levels of decisional conflict,[20] and 74% of the sample reported DCS scores within the clinically significant range. The DCS mean was also well above the ideal DCS cutoff score of 25, which is associated with implementing decisions.[20]

As expected, the DSE and DCS scales were negatively correlated ($r = -0.52$, $p < 0.001$); higher levels of confidence in making family-building decisions (decision self-efficacy) related to lower decisional conflict about family building.

3.5 | Primary analyses

Two regression models were specified to understand correlates of decision self-efficacy and decisional conflict in reference to family-building decisions. In both models, Step 1 included age, years since treatment, post-treatment fertility evaluation (yes/no), and unmet information needs (UIN) as covariates; and Step 2 included reproductive concerns (RCACS) and avoidance (IES-A) as independent variables (see Table 3).

In the first model predicting decision self-efficacy (DSE), greater reproductive distress ($B = -0.23$, $p = 0.04$) and higher levels of avoidance ($B = -0.24$, $p = 0.02$) related to lower decision self-efficacy. The model accounted for 20% of the variance in decision self-efficacy ($F[6,85] = 4.89$, $p < 0.001$). No covariates were related to decision self-efficacy in this model.

In the second model predicting decisional conflict (DCS), younger age ($B = -0.18$, $p = 0.03$), greater unmet information needs ($B = 0.33$, $p < 0.001$), and higher levels of reproductive distress ($B = 0.34$, $p = 0.001$) related to higher levels of decisional conflict; avoidance was not significant ($B = 0.12$, $p = 0.15$). The model accounted for 43% of the variance in decisional conflict ($F[6,84] = 12.59$, $p < 0.001$).

3.6 | Factors related to reproductive distress

Higher levels of reproductive distress related to identifying as Hispanic/Latina (vs. non-Hispanic white, $t[105] = -1.94$, $p = 0.05$), lower education (high school degree or vocational school vs. college/graduate degree; $F[2105] = 3.11$, $p = 0.05$), lower income (<\$50,000 vs. >\$100,000; $F[2,90] = 4.14$, $p = 0.02$), fewer years since treatment ($r = -0.22$, $p = 0.02$), and a belief that cancer treatment negatively impacted fertility ($t[106] = -2.58$, $p = 0.01$). Women who were not satisfied with provider discussions about fertility ($t[94] = -3.60$, $p = 0.001$), infertility risks ($t[94] = -2.68$, $p = 0.01$), and family-building options ($t[87] = -3.77$, $p < 0.001$) reported higher levels of reproductive distress, compared to those who were satisfied with provider discussions (those indicating they were uninterested in discussions or did not remember were excluded). Higher levels of reproductive distress related to having greater unmet fertility information needs ($r = 0.41$, $p < 0.001$), higher levels of avoidance ($r = 0.32$, $p = 0.001$), lower decision self-efficacy ($r = -0.30$, $p < 0.01$), and higher decisional conflict ($r = 0.43$, $p < 0.001$). Women scoring in the clinically significant range of decisional conflict reported significantly higher reproductive distress ($M = 62.56$, $SD = 10.32$) than those with lower decisional conflict ($M = 54.04$, $SD = 8.64$; $t[106] = -3.92$, $p < 0.001$). Reproductive distress was not related to age, race, employment status, or having had a prior fertility evaluation since cancer treatment ended.

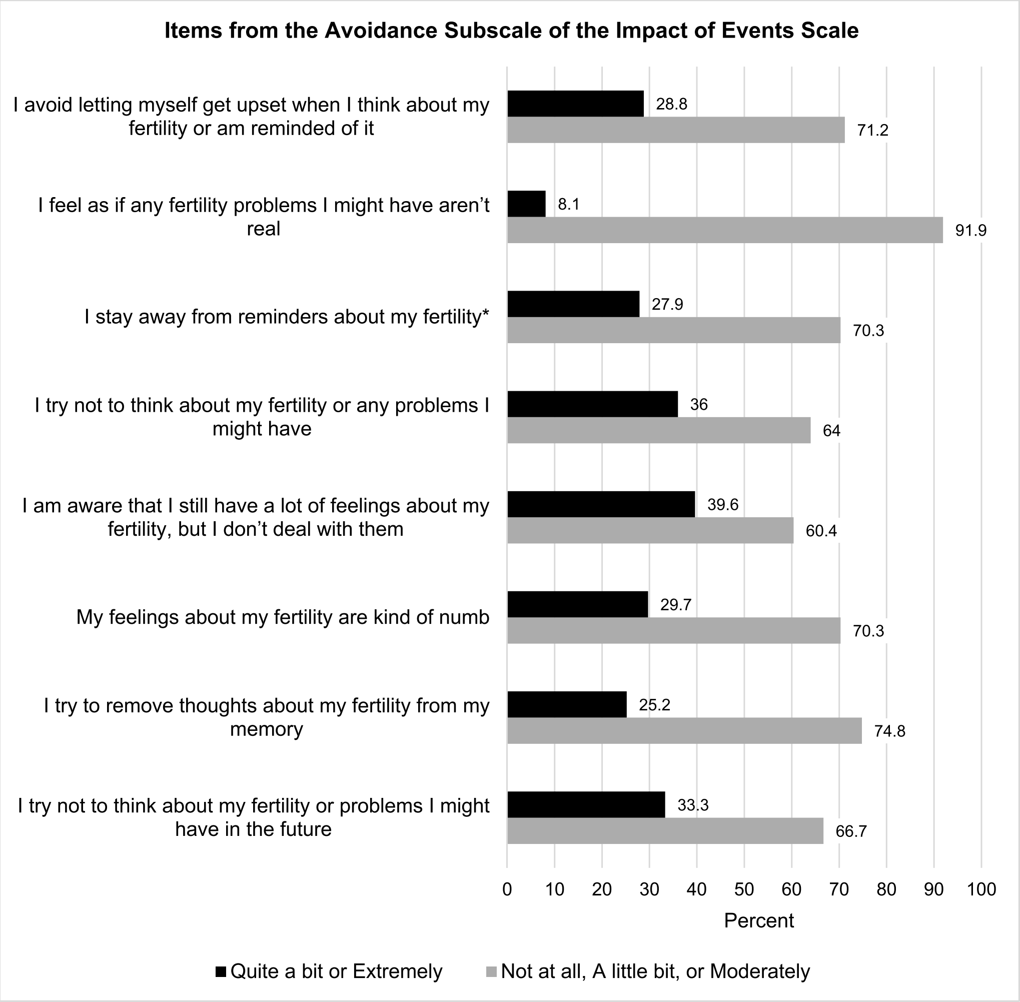

FIGURE 1 Avoidance as a response to oncofertility stress.

3.7 | Factors related to avoidance

Higher levels of avoidance related to identifying as non-white (i.e., Black, Asian, and multiracial; subgroups combined due to small numbers; $t[108] = -2.27$, $p = 0.03$) and Hispanic/Latina (vs. non-Hispanic white; $t[108] = -2.27$, $p = 0.03$), and lower education ($t[109] = 3.13$, $p = 0.002$). Women who were not satisfied with provider discussions about fertility ($t[96] = -2.53$, $p = 0.01$) and about family-building options ($t[89] = -2.31$, $p = 0.01$) reported higher levels of avoidance, compared to those who were satisfied with provider discussions. Greater avoidance related to lower decision self-efficacy ($r = 0.33$, $p < 0.001$) and higher decisional conflict ($r = 0.24$, $p = 0.01$). Those who scored within the clinically significant range of decisional conflict reported significantly higher levels of avoidance ($M = 1.75$, SD = 0.88) compared to those that reported lower decisional conflict ($M = 1.21$, SD = 0.79; $t[109] = -2.91$, $p = 0.004$). Avoidance was not related to age, employment status, income, years since treatment, prior fertility evaluation since cancer treatment completed, and unmet information needs.

4 | DISCUSSION

This study evaluated AYA-Fs' experiences in post-treatment survivorship related to fertility and family building after cancer. AYA-Fs reported moderate to high rates of unmet oncofertility information needs, moderate to high levels of reproductive distress, and a substantial subgroup reported avoidance of fertility/family-building stressors, all of which related to poorer quality decision making about family building after cancer. This study helps to identify modifiable targets of intervention to support survivors in managing their fertility concerns and empowering them to make decisions that will enable future parenthood.

Findings suggest that many AYA-F survivors struggle with making decisions about fertility care and family-building options after cancer (via reproductive medicine or adoption) as expressed in high rates of decisional conflict, and, in about a third of the sample, decreased decisional self-efficacy. In this study, survivors with greater unmet information needs and reproductive distress reported more decisional conflict, and lower self-efficacy was seen by those

TABLE 3 Multiple regression analysis to evaluate correlates of decision-making processes about family building after cancer ($N = 111$).

	R^2	R^2 Δ	B	SE	β	t	p
Model 1							
DV: Decision self-efficacy (DSE), F(6,85) = 4.89, $p < 0.001$							
Step 1	0.15						
Constant			120.72	20.74		5.82	<0.001
Age at survey (years)			0.004	0.40	0.001	0.01	0.99
Time since treatment (years)			−0.68	0.44	−0.16	−1.56	0.12
Fertility evaluation (0 = no/unsure)			7.47	4.71	0.16	1.59	0.12
Unmet fertility information needs			−1.89	1.36	−0.15	−1.39	0.17
Step 2	0.26	0.11					
Reproductive distress (RCACS)			−0.54	0.26	−0.23	−2.07	0.04
Avoidance (IES-A)			−6.64	2.66	−0.24	−2.49	0.02
Model 2							
Decisional conflict (DCS), F(6,85) = 12.59, $p < 0.001$							
Step 1	0.37						
Constant			7.88	18.67		0.42	<0.001
Age at survey (years)			−0.78	0.36	−0.18	−2.18	0.03
Time since treatment (years)			−0.24	0.39	−0.05	−0.62	0.54
Fertility evaluation (0 = no/unsure)			−5.10	4.24	−0.10	−1.20	0.23
Unmet fertility information needs			4.49	1.23	0.33	3.66	<0.001
Step 2	0.47	0.11					
Reproductive distress (RCACS)			0.85	0.24	0.34	3.61	0.001
Avoidance (IES-A)			3.49	2.40	0.12	1.46	0.15

Note: $F[6,85] = 4.89$, $p < 0.001$.

Abbreviations: DCS, Decision Conflict Scale; DSE, Decision Self-Efficacy scale; DV, dependent variable; IES-A, Impact of Events – Avoidance subscale; RCACS, Reproductive Concerns After Cancer Scale; SE, standard error.

reporting more distress and avoidance. In turn, being unsatisfied with provider discussions about these topics contributed to distress and avoidance. Survivors may benefit from decision support or counseling to help them make sense of their options including intermediary steps to access medical services, learn about a preferred family-building pathway (and potential barriers to prepare for), or to intentionally delay the decision. They may also benefit from learning strategies to manage negative affect and build confidence in their ability to make and implement decisions.

Many survivors indicated some level of avoidant coping as a response to oncofertility stress. For comparison, the mean score of the IES-R Avoidant subscale was higher than the published mean of breast and gynecologic cancer patients reporting avoidance in response to their cancer diagnosis as the triggering stressor.[22] In a qualitative study, Canzona et al. found that AYA cancer survivors avoided thinking about fertility and avoided conversations with providers about fertility as a way to manage uncertainty and avoid discomfort.[23] In their conceptual model, emotional experiences impacted coping strategies, including avoidance, and both impacted decision making about fertility preservation before cancer treatment.[23] Likewise, in our study, reproductive distress and avoidant coping were positively correlated and both negatively affected decisional processes about family building. Avoidance is a common practice in the face of a distressing event and is often conceptualized as a coping tool.[24–26] Avoidant coping can be a useful way of managing negative affect elicited by a potential health threat and to maintain a sense of hope and optimism in the face of health risk uncertainty.[24,26,27] However, when avoidance persists and underlying negative emotions are not addressed or personal decision making about one's health or health goals is jeopardized, it may become problematic. Avoidance of cancer-related topics has been associated with higher levels of depression and anxiety, less use of emotional support, and may lead to self-blame.[13] We previously reported that "fear of receiving bad news" was one reason AYA-Fs chose to forego a fertility evaluation in post-treatment survivorship.[3] For some women, avoidant behaviors may interfere with information seeking or access to time-dependent reproductive health care and lower the chances of reproductive success.

In this study, non-white minoritized women and those with lower education reported higher levels of reproductive distress and more avoidance than non-Hispanic white women and those with higher education, respectively. Prior research identified social determinants of avoidance among cancer survivors, in which younger age, being female, greater debt and lower income, and more difficulty finding suitable information related to higher likelihood of avoidance of cancer information after a diagnosis.[28] Minority groups and those from socially and economically disadvantaged populations also face greater barriers to access and are substantially less likely to use assisted reproductive health services.[29–31] There is an urgent need to take steps to address historical and structural barriers and ensure equitable access to oncofertility services in the U.S., such as improving insurance coverage. At the same time, young adult survivors report feeling overwhelmed by survivorship care recommendations and ill-equipped to navigate healthcare systems.[11,32] Cancer information overload and anxiety are both associated with greater avoidance.[33] Cancer survivorship care must address the informational, emotional, and supportive needs of survivors, which may vary by sociodemographic and clinical factors. Tailored strategies are needed to ensure information is accessible to vulnerable groups such as those from lower socioeconomic positions. As well, beyond the mere provision of information, findings suggest the importance of helping AYA-Fs cope with oncofertility stressors that may include structural and system-level barriers. Future work is needed to understand the oncofertility experiences and barriers of minoritized and underserved patient population.

It is well accepted that oncofertility should be a part of cancer survivorship care.[34] There are a number of decision support interventions that have shown benefit for pre-treatment decision making about fertility preservation.[35] These may be adapted to the post-treatment context in which survivors face decisions about family building when reproductive medicine or adoption is needed. Benedict et al. developed the web-based 'Roadmap to Parenthood' decision aid and planning tool for family building after cancer,[36,37] and in two pilot studies the tool led to positive effects on decision-making outcomes as well as improved self-efficacy for managing fertility-related emotions (under review).[38] Decision aids have been shown to be effective in a number of health contexts including with socially disadvantaged populations.[39–41] Focusing on the post-treatment time period, a 12-week psycho-educational intervention for fertility-related distress and sexual health among childhood cancer survivors (Fex-Can) reported better cancer-related fertility knowledge in the intervention group compared to a control group, but there were no differences in reproductive distress.[42] As AYA-Fs learn new information about the challenges of family building after cancer, it is appropriate to experience negative emotions, and targeting emotion regulation strategies may be an important skill.

Strategies to reduce health information avoidance may also be helpful for survivors facing oncofertility risks and stressors. In one study, patients prompted to reflect on positive coping strategies and past coping successes were less likely to avoid threatening health information about disease risk compared to a control condition.[27] Therapeutic techniques based in Acceptance and Commitment Therapy (ACT) may be promising. Through ACT, people learn how to adapt to changing situational demands, reconfigure mental resources, shift perspectives, and make decisions aligned with their values, to ultimately better equip them to engage with unforeseen, unwanted, or unavoidable factors.[43,44] As such, ACT may help AYA-Fs adjust their expectations for how parenthood may be achieved, approach family building with a new perspective, feel more prepared to adapt to new or unexpected information or events as part of family-building pursuits, and ultimately feel more capable of managing fertility/family-building stressors. ACT has shown promise in reducing anxiety and fear of recurrence in cancer patients.[45,46] Alternatively, as survivors have reported existential distress related to oncofertility concerns (e.g., loss of womanhood, identity renegotiation, and loss of meaning and purpose), Meaning-Centered Psychotherapy may help survivors identify sources of meaning in reaction to their new reality of post-cancer fertility changes and altered family-building options.[47,48] Future work should explore whether similar approaches may be used in oncofertility situations, which may be combined with decisional support resources or coaching to address emotional experiences and decision-making needs.

4.1 | Study limitations

Study limitations include the cross-sectional design, which precludes causal inferences and did not allow us to explore temporal relationships. The sample was primarily white and well-educated, and we were limited in our ability to evaluate subgroup differences based on race, ethnicity, and socioeconomic status. As this was a nationwide self-report survey study, we were unable to obtain objective medical data about fertility experiences and outcomes. Future studies should explore these relationships with comprehensive oncofertility data over time and within diverse populations of survivors.

4.2 | Clinical implications

Our data suggest many AYA-F survivors have unmet informational and emotional support needs about fertility and family building after cancer and report uncertainty when considering decisions about reproductive medicine or adoption. Minoritized women and those with lower education may face greater challenges when facing oncofertility issues. Improved patient-provider communication about post-cancer fertility care, such as asking patients about their reproductive concerns and family-building plans, and referral to appropriate medical care, counseling, and/or patient resources may help to mitigate some of these challenges.

5 | CONCLUSION

AYA-F survivors need more information and support to understand their fertility and parenthood options after cancer, manage negative emotions, and make decisions that are aligned with their values, priorities, and goals. Longitudinal studies are needed to better understand survivors' evolving needs and decision-making processes as they consider fertility and family-building options after cancer. Understanding the experiences and barriers of vulnerable populations in particular is needed to develop tailored approaches to support survivors from diverse and underserved groups.

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CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest to report.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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