

Open camera or QR reader and
scan code to access this article
and other resources online.



The Impact of Cancer-Related Financial Toxicity on Reproductive Concerns and Family-Building Decision-Making in Post-Treatment Survivorship

Catherine Benedict, PhD,^{1,2} Bridgette Thom, PhD,³ Michael Diefenbach, PhD,⁴
Lidia Schapira, MD,² Pam Simon, MSN, CPNP, CPON,⁵ and Jennifer S. Ford, PhD⁶

Purpose: Adolescent and young adult (AYA) survivors are at-risk for cancer-related financial difficulties (i.e., financial toxicity [FT]). Family building after cancer often requires reproductive medicine or adoption with high costs; AYAs experience financial barriers to family building. This study evaluated the relationships among cancer FT, reproductive concerns, and decision-making processes about family building after cancer.

Methods: AYA female (AYA-F) cancer survivors completed a cross-sectional survey including measures of FT, reproductive concerns, decisional conflict about family building, and decision-making self-efficacy. Differences across FT subgroups (i.e., no/mild, moderate, and severe FT) were tested. Linear regression evaluated the relationships between FT and reproductive concerns and decision-making processes.

Results: Participants ($N=111$) averaged 31.0 years (standard deviation [SD]=5.49), 90% were nulliparous, and 84% were employed full/part-time. The overall FT levels were in the “moderate” range ($M=20.44$, $SD=9.83$); 48% worried *quite a bit* or *very much* about financial problems because of cancer. AYA-Fs reporting severe FT (24% of sample) experienced higher levels of reproductive concerns compared with those reporting no/mild and moderate FT. Those reporting moderate FT (46% of sample) reported greater decisional conflict about family-building options, compared with the no/mild FT subgroup. Both moderate and severe FT subgroups reported lower decision-making self-efficacy compared with the no/mild FT subgroup. In separate models controlling for covariates, greater FT related to higher levels of reproductive concerns ($B=-0.39$, $p<0.001$), greater decisional conflict about family building ($B=-0.56$, $p=0.02$), and lower decision-making self-efficacy ($B=0.60$, $p=0.01$).

Conclusions: Given the high costs of reproductive medicine and adoption, fertility counseling pre- and post-treatment must address survivors’ financial concerns and barriers.

Keywords: fertility, oncofertility, financial toxicity, cancer survivorship

Introduction

ADOLESCENT AND YOUNG ADULT (AYA; 15–39 years old) cancer survivors are an at-risk group for experiencing treatment-related financial toxicity (FT), including direct (e.g., out-of-pocket expenses, medical debt, and ongoing health care costs) and indirect (e.g., missed work and loss of

income) financial effects, subjective financial stress, and cost-coping behaviors (e.g., missed visits and nonadherence to medications).^{1,2}

Compared with older patients, AYA survivors report higher FT, including greater material hardship, more cost-coping behaviors, and worse associated psychological burden.^{3–6} They also report lower education and income, are

¹Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Palo Alto, California, USA.

²Stanford Cancer Institute, Stanford, California, USA.

³Memorial Sloan Kettering Cancer Center, New York, New York, USA.

⁴Donald and Barbara Zucker School of Medicine at Hofstra/Northwell, Manhasset, New York, USA.

⁵Lucile Packard Children’s Hospital Stanford, Palo Alto, California, USA.

⁶Hunter College and The Graduate Center, City University of New York (CUNY), New York, New York, USA.

more likely to be under- and unemployed and lack insurance coverage, and have greater medical debt and out-of-pocket medical expenses compared with noncancer peers.⁷ Female sex and younger age are both associated with greater FT after cancer.^{6,8} Age-related financial pressures, such as tuition, student loans, and low early career salary, may exacerbate financial stress. In a study conducted during the covid-19 pandemic, half of all AYAs reported severe FT and 71% reported medical-related cost-coping behaviors.⁹

Simultaneously, many AYAs will experience impaired fertility and disrupted family building due to gonadotoxic treatments, risks associated with pregnancy, and/or the need for teratogenic maintenance therapies. Thus, family building may require the use of assisted reproductive technology (ART) to achieve pregnancy in the intended parent or a gestational carrier, fostering, or adoption. In the United States, current cost estimates range from \$12,000 to \$26,000 per *in vitro* fertilization (IVF) cycle (or \$30,000 to \$60,000 for IVF-donor egg cycles) and \$40,000 to \$85,000 per live birth using IVF, as more than one cycle is often needed; \$100,000 to \$150,000 for gestational carrier; and \$20,000 to \$70,000 for adoption.^{10–13} Total costs can be difficult to predict, however, given the uncertainty surrounding the ART procedures needed (e.g., number of IVF cycles to achieve pregnancy), extent of insurance coverage, and legal and logistical difficulties, particularly, with surrogacy and adoption (e.g., lawyer fees, travel).

Although some states have passed laws mandating insurance coverage for some fertility treatments, coverage for most is still limited or nonexistent.¹⁴ While there are some compassionate care discounts and cancer charity grants for pre-treatment fertility preservation,¹⁵ financial support opportunities for post-treatment family building are rare.

This study evaluated relationships among cancer-related FT, reproductive concerns, and decision-making processes about family building among AYA female (AYA-F) cancer survivors. It was hypothesized that greater FT would relate to higher levels of reproductive concerns, greater uncertainty about family-building decisions, and lower self-efficacy for making family-building decisions after cancer.

Methods

Secondary analyses of a mixed-methods study examining AYA-F fertility and family-building experiences after cancer were conducted.¹⁶ Study procedures were approved by the Northwell Health Institutional Review Board.

Participants

Eligibility criteria included the following: (i) female sex assigned at birth, (ii) age 15–45 years, (iii) cancer history and completion of gonadotoxic treatment (e.g., systemic chemotherapy and/or pelvic radiation), (iv) had not had a child since cancer diagnosis, and (v) reported parenthood desires or undecided family-building plans. AYA-Fs could have been on long-term adjuvant or endocrine treatment or currently pregnant (or a surrogate was pregnant).

Procedure

Hospital-based recruitment identified patients through electronic medical records, and introductory letters were

mailed. Study advertisements were also posted on patient organizations' social media pages (e.g., Stupid Cancer, Laccuna Loft) with a link to provide contact information using an HIPAA-compliant platform. Follow-up calls confirmed eligibility and completed enrollment. Parental consent and participant assent were obtained for minors. Following enrollment, participants were emailed a link to complete a survey online through REDCap.

Measures

Standard questionnaires collected sociodemographic and medical information. FT was measured using the Comprehensive Score for Financial Toxicity (COST; 11 items), assessing cancer-related financial impact including direct costs related to cancer care (e.g., out-of-pocket expenses) and indirect costs (e.g., employment changes, loss of income).¹⁷ Total scores range from 0 to 44; lower scores represent worse financial outcomes. Prior work has defined three levels of FT: no/mild (COST scores ≥ 26), moderate (COST scores 14–25), and severe (COST scores 0–13).¹⁸ Reproductive concerns were measured by the Reproductive Concerns After Cancer Scale (RCACS; 18 items), which includes the following 6 domains: fertility potential, becoming pregnant, personal health, child's health, partner disclosure, and acceptance.¹⁹ RCACS mean scores range from 18 to 90, with higher scores indicating higher levels of concern.

Decision-making was measured using two scales. The Decisional Conflict Scale (DCS; 16 items) assesses personal uncertainty in making health decisions and includes the following 5 domains: feeling uncertain, feeling uninformed, feeling unclear about values, feeling unsupported, and ineffective decision-making.^{20,21} The Decision Self-Efficacy (DSE) Scale (11 items) measures the 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).²² 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 DSE.

Data analysis

Descriptive statistics characterized the sample and patient-reported outcomes. Bivariate relations were evaluated with Pearson's correlations, *t*-tests, and ANOVAs. Subgroup analysis looked at differences across COST grading scale categories (i.e., none/mild, moderate, severe FT). Linear regression evaluated relationships between FT and reproductive concerns and decision-making processes, controlling for *a priori* covariates.

Results

Participants ($N=111$) were on average 31.0 years old (standard deviation [SD]=5.49; range 15–45), median 3 years post-treatment ($M=6.12$, $SD=5.63$, range: 1–23 years), and 84% were employed full/part-time. Most (76%) identified as white and 18% were Hispanic/Latina. Annual household income included 34% reporting $< \$50,000$, 31% reporting \$50,000 to \$100,000, and 22% reporting

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		
Less than \$50,000	38	34.2
\$50,000 to \$100,000	34	30.6
Greater than \$100,000	24	21.6
Unknown	4	3.6
Prefer not to answer	11	9.9
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

(continued)

TABLE 1. (CONTINUED)

	Mean (SD)	Range
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 ^{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 don't 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%), and 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.

> \$100,000, with 13% unknown or opting out. Most common diagnoses were hematologic malignancies (49%) and breast cancer (22%). Most were nulliparous (90%), and 16% had undergone fertility preservation before treatment (Table 1).

Women reported high levels of reproductive concern ($M=60.4$, $SD=10.56$) that were comparable with prior studies of young adult female cancer survivors.^{23,24} Decisional conflict about family building was high ($M=52.1$, $SD=23.87$), exceeding the cutoff score of 37.5 in which higher scores are associated with decision delay or feeling unsure about implementation,²¹ and the DSE scores averaged 70.5 ($SD=22.91$; range 0–100).

The overall levels of FT were in the “moderate” range ($M=20.45$, $SD=9.83$; median=20.45; range=1.44–42); 27% reported no/mild FT, 46% reported moderate, and 24% reported severe FT (3% [$n=3$] had missing COST data). Item-level analysis indicated that 48% worried *quite a bit* or *very much* about financial problems because of cancer, 40% felt financially stressed *quite a bit* or *very much*, and 21% reported being able to meet monthly expenses *not at all* or *a little bit*. Worse FT related to Hispanic/Latina ethnicity ($t[108]=3.03$, $p=0.003$), lower educational attainment ($F[4,106]=2.59$, $p=0.04$), and lower household income ($F[4,106]=7.08$, $p<0.001$). Levels of FT were not related to age, race, employment status, locality (i.e., self-reported as urban, suburban, or rural), time since cancer treatment, comorbid illness(es), or nulliparity (all $ps>0.10$).

Subgroup analysis tested differences in reproductive concerns and decision-making processes based on previously defined COST levels of FT (i.e., three-group comparison of those reporting no/mild, moderate, and severe FT). AYA-Fs reporting severe FT experienced higher levels of reproductive concerns compared with those reporting no/mild FT and moderate FT ($F[2,102]=10.85$, $p<0.001$).

With respect to decision-making, those reporting moderate FT reported greater decisional conflict about family building compared with the no/mild FT subgroup; those reporting severe FT also reported greater decisional conflict than the no/mild FT subgroups at the trend level ($F[2,105]=3.89$, $p=0.02$). Notably, all FT subgroups still scored above the threshold for clinically significant decisional conflict (i.e., cutoff score of 37.5).²¹ Both moderate and severe FT subgroups reported lower DSE about family building compared with the no/mild FT subgroup ($F[2,105]=5.19$, $p=0.007$) (Fig. 1).

Three regression models were specified to evaluate the relationships between FT and reproductive concern (model 1), decisional conflict (model 2), and DSE (model 3), controlling for *a priori* covariates including age, education (high school/vocational vs. college/graduate), employment (full/part-time vs. not employed), time since treatment, and post-treatment fertility evaluation status (yes/no) (Table 2). In model 1, worse FT related to higher levels of reproductive concern ($B=-0.39$, $p<0.001$) and the model accounted for 21% of the variance in the RCACS. In model 2, worse FT related to greater decisional conflict about family-building options ($B=-0.56$, $p=0.02$) and the model accounted for 14% of the variance in the DCS; those who had not undergone a fertility evaluation also reported greater decisional conflict ($B=-10.33$, $p=0.04$).

In model 3, worse FT related to lower decision-making self-efficacy ($B=0.60$, $p=0.01$), and the model accounted for 22% of the variance in the DSE; lower education ($B=15.91$, $p=0.02$); and not having had a fertility evaluation ($B=9.12$, $p=0.05$) also related to lower DSE.

Discussion

This is the first study to our knowledge to quantitatively examine the associations of cancer-related financial experiences with post-treatment decisions about family-building options (i.e., IVF or surrogacy with fresh/frozen/donated gametes or adoption/fostering). In this study of AYA-F cancer survivors who had received gonadotoxic treatment, worse cancer-related FT related to higher levels of reproductive concerns and greater uncertainty and lower confidence about making family-building decisions. Given the high costs typically associated with family building through reproductive medicine or adoption, fertility counseling should include survivors' financial concerns and barriers, particularly after completion of cancer treatment.

Findings highlight the ways in which cancer-related financial stressors may impact other areas of survivors' lives. AYA-Fs in this study reported comparable levels of FT as other studies.^{6,25-27} The financial effects of cancer are known to disrupt normative young adult development, including achievement of milestones and future goals.²⁸ There is no indication that cancer or financial stressors dissuade survivors from wanting children, and, in fact, they may have greater motivation to do so as a source of normality after cancer and hope about the future.^{29,30} At the same time, AYA-Fs often feel uninformed about their fertility and family-building options, including a potentially shortened reproductive time line and accurate estimations of the high costs of ART and adoption.³¹ AYA-Fs report a need for fi-

ancial support and counseling when considering family-building decisions, which was described as a "serious financial decision."³²

Thus, AYAs may experience a "perfect storm" of financial stressors stemming from cancer FT effects and the high costs of family building. These issues may be compounded by a lack of information and counseling, added pressures associated with advancing age, narrowed reproductive time window (i.e., risk of premature ovarian failure), and expectations about life trajectory, all of which can limit the amount of time available to save money or plan financially and add to the decision-making uncertainty.

Prior studies have shown high costs to be critical in decision-making about fertility preservation and a frequent barrier to pursuing such options before cancer treatment.^{33,34} In addition, having undergone egg or embryo freezing before cancer treatment increases survivors' risk of financial vulnerability and experiencing debt after treatment.³⁵ This study builds on these findings and demonstrates the impact of financial factors on family-building decisions in post-treatment survivorship. AYA-Fs reported levels of decisional conflict about family building that exceeded the validated cutoff score (>37.5) associated with decision delay, feeling unsure about implementing decisional outcomes, and having a greater likelihood of blaming one's provider when negative outcomes occur.²¹

We previously reported that young adult survivors who tried to have a child through reproductive medicine or adoption experienced significant distress, including feeling unprepared for the high costs and describing emotional pain, anger, and regret.³⁶ They also relayed uncertainty about how to fulfill their dreams of parenthood while still being financially responsible, including the awareness of perceived financially risky decisions and reluctant willingness to deplete savings and incur debt.³⁶ Survivors may struggle with making decisions about how to spend limited financial resources, highlighting both the objective material hardship and subjective emotional experiences (e.g., worry, rumination) of financial problems and decision-making difficulty.

AYAs report a need for education about how to manage cancer costs and insurance issues and to improve financial literacy.^{37,38} Survivors also want financial information about family-building options to be provided as a part of fertility counseling within cancer care.³² Increasingly, it is recognized that conversations about treatment costs and financial trade-offs are important components of health care, with multiple strategies put forth to improve the ways in which financial issues are managed (e.g., teaching clinicians to initiate cost conversations, systematic screening for financial distress, use of financial navigators).^{39,40} Cost conversations are important for at-risk or disadvantaged populations, particularly in this context, as minoritized groups based on race/ethnicity, gender identity, and sexual orientation are more likely to experience barriers in access to reproductive medicine, including fertility preservation after a cancer diagnosis.⁴¹⁻⁴³

There have been efforts to create lower cost treatment protocols, specifically aimed to increase access among low-resource populations,⁴⁴ but these are limited. Insurance often fails to cover ART procedures, and systems-level changes are

FIG. 1. Subgroup differences in reproductive concern and decision-making processes based on FT categories. **(a–c)** AYA-F cancer survivors reporting severe FT experienced higher levels of reproductive concerns compared with those reporting no/mild FT and moderate FT. Those reporting moderate FT reported greater decisional conflict about family-building options. Both moderate and severe FT subgroups reported lower decision-making self-efficacy compared with the no/mild FT subgroup. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$. AYA-F, adolescent and young adult female; FT, financial toxicity.

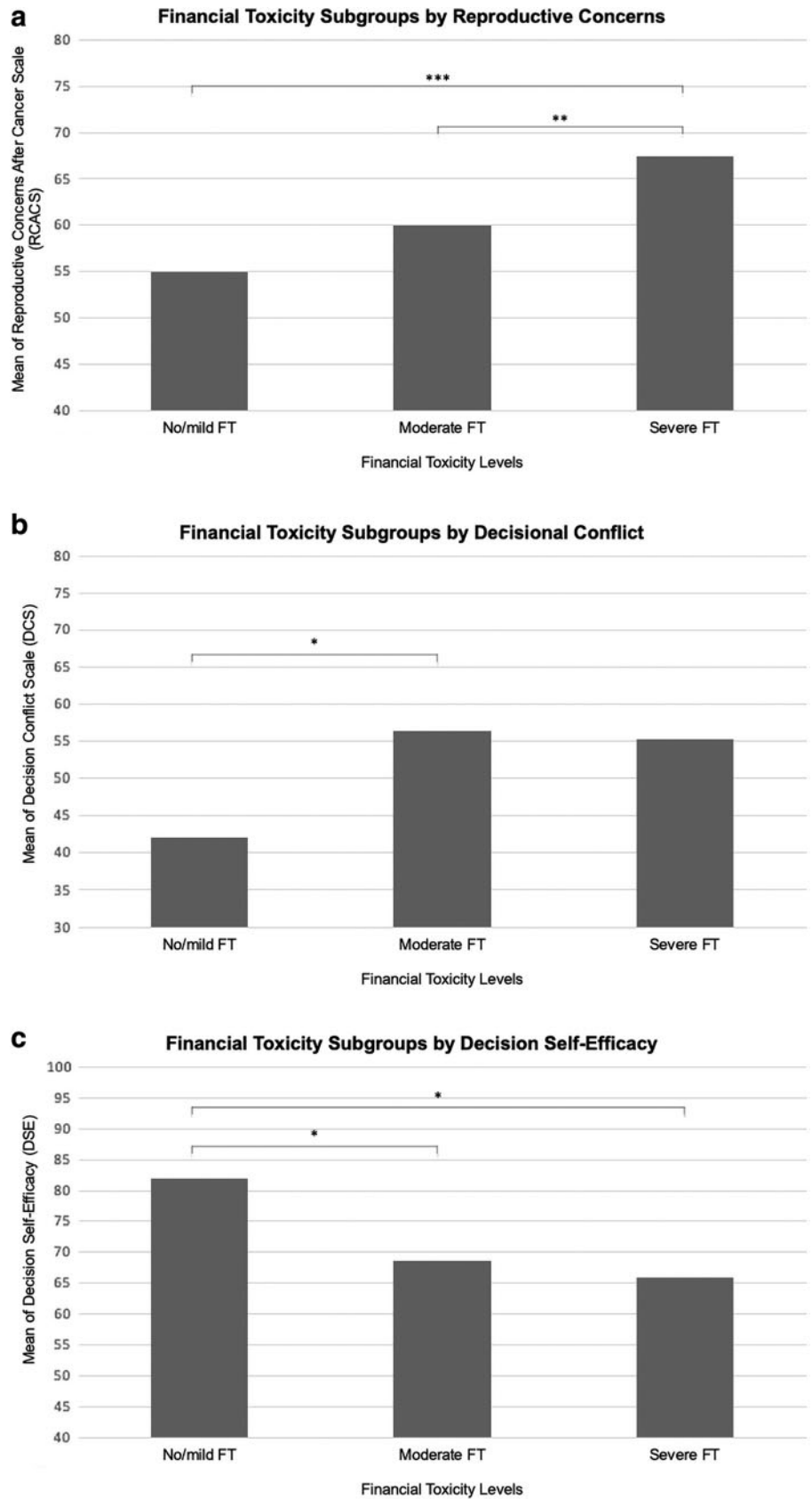


TABLE 2. MULTIPLE REGRESSION ANALYSIS TO EVALUATE THE EFFECTS OF FINANCIAL TOXICITY ON REPRODUCTIVE CONCERNS AND DECISION-MAKING PROCESSES ABOUT FAMILY BUILDING AFTER CANCER (N=111)

		R ²	R ² Δ	B	SE	β	t	p
Model 1 ^a								
DV: Reproductive concerns ($F[7,94]=3.57, p=0.002$)								
1	Constant	0.21	0.13	77.38	5.86			
	Age at survey, years			-0.20	0.18	-0.11	-1.11	0.27
	Race (0=white)			-1.98	2.32	-0.08	-0.85	0.40
	Education (0=high school/vocational)			-0.57	2.83	-0.02	-0.20	0.84
	Employment (0=unemployed)			0.25	2.75	0.01	0.09	0.93
	Time since treatment, years			-0.25	0.17	-0.14	-1.45	0.15
	Fertility evaluation (0=no/unsure)			-2.08	2.11	-0.10	-0.99	0.33
2	Financial toxicity (COST)			-0.39	0.10	-0.38	-3.92	<0.001
Model 2 ^a								
Decisional conflict ($F[7,97]=2.29, p=0.03$)								
1	Constant	0.14	0.05	92.32	14.22			
	Age at survey, years			-0.81	0.43	-0.19	-1.88	0.06
	Race (0=white)			-2.02	5.59	-0.04	-0.36	0.72
	Education (0=high school/vocational)			-0.22	6.95	-0.003	-0.03	0.98
	Employment (0=unemployed)			1.11	6.77	0.02	0.16	0.87
	Time since treatment, years			-0.08	0.42	-0.02	-0.19	0.85
	Fertility evaluation (0=no/unsure)			-10.33	5.07	-0.21	-2.04	0.04
2	Financial toxicity (COST)			-0.56	0.24	-0.23	-2.35	0.02
Model 3 ^a								
Decision self-efficacy ($F[7,97]=3.99, p=0.001$)								
1	Constant	0.22	0.06	54.98	13.10			
	Age at survey, years			-0.34	0.40	-0.08	-0.85	0.40
	Race (0=white)			4.99	5.15	0.09	0.97	0.34
	Education (0=high school/vocational)			15.91	6.41	0.26	2.48	0.02
	Employment (0=unemployed)			1.04	6.23	0.02	0.17	0.87
	Time since treatment, years			-0.72	0.38	-0.17	-1.87	0.06
	Fertility evaluation (0=no/unsure)			9.12	4.67	0.19	1.96	0.05
2	Financial toxicity (COST)			0.60	0.22	0.25	2.69	0.01

^aA priori covariates included age, race (two groups: white vs. all other racial groups), education (high school/vocational vs. college/graduate), employment (full/part-time vs. not employed), time since treatment, and whether they had undergone a fertility evaluation since cancer treatment ended (yes/no).

COST, Comprehensive Score for Financial Toxicity; DV, dependent variable; SE, standard error.

needed to expand coverage and address rising cost-sharing practices.⁴⁵ There is a recognized need for tailored FT management as a part of patient-centered cancer care⁴⁶; for AYAs who received gonadotoxic therapies and hope to have a child (or more children), this should also include discussion about family-building options and costs.

Study limitations include the cross-sectional design, which precludes causal inferences and did not allow us to explore temporal relationships between FT and outcomes of interest. The study also included a relatively small convenience sample that was 76% white. Other population-based studies of AYA cancer incidence have reported 80%–88% white participants.^{47,48} We did not collect objective measures of FT (e.g., out-of-pocket estimates, percent of income spent on medical care), insurance coverage, or partner-level factors that may impact family-building experiences. These data are often not revealed by participants who are completing online surveys, and thus we decided not to include them.

Future studies should explore these relationships with comprehensive financial data over time, particularly among minoritized groups and those most at-risk for experiencing

cancer-related FT and compared with noncancer peers. A comparison of family-building costs between those who preserved their fertility (e.g., have frozen eggs/embryos to use) versus those who did not may also be important to inform the decision-making and family-building processes.

Decisions about fertility and family building after cancer are complex, involving reproductive medicine or adoption processes with high costs. The present findings highlight the ways in which cancer-related financial effects may exacerbate difficulties survivors face as they navigate the process of achieving parenthood, and lead to financial barriers and increased stress for survivors. Survivors may benefit from financial support resources, such as information about grants, financial skills training, or financial counseling, to address financial stressors and better enable financial planning for future family building. Continued advocacy for insurance coverage for fertility preservation and ART procedures is needed to help alleviate financial barriers.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

This research was supported by grants from the National Cancer Institute R03CA212924 (PI: Catherine Benedict) and K07CA229186 (PI: Catherine Benedict). BT was funded in part through the NIH/NCI Cancer Center Support Grant P30 CA008748.

References

- Lu AD, Zheng Z, Han X, et al. Medical financial hardship in survivors of adolescent and young adult cancer in the United States. *J Natl Cancer Inst* 2021;113(8):997–1004; doi: 10.1093/jnci/djab013.
- Salsman JM, Bingen K, Barr RD, et al. Understanding, measuring, and addressing the financial impact of cancer on adolescents and young adults. *Pediatr Blood Cancer* 2019; 66(7):e27660; doi: 10.1002/pbc.27660.
- Zheng Z, Han X, Zhao J, et al. Financial hardship, healthcare utilization, and health among U.S. cancer survivors. *Am J Prev Med* 2020;59(1):68–78; doi: 10.1016/j.amepre.2020.02.016.
- Meeker CR, Wong YN, Egleston BL, et al. Distress and financial distress in adults with cancer: An age-based analysis. *J Natl Compr Cancer Netw* 2017;15(10):1224–1233; doi: 10.6004/jnccn.2017.0161.
- Corrigan KL, Fu S, Chen YS, et al. Financial toxicity impact on younger versus older adults with cancer in the setting of care delivery. *Cancer* 2022;128(13):2455–2462; doi: 10.1002/cncr.34220.
- Hastert TA, Ruterbusch JJ, Abrams J, et al. Financial hardship by age at diagnosis including in young adulthood among African American cancer survivors. *Cancer Epidemiol Biomarkers Prev* 2022;31(4):876–884; doi: 10.1158/1055-9965.EPI-21-0739.
- Landwehr MS, Watson SE, Macpherson CF, et al. The cost of cancer: A retrospective analysis of the financial impact of cancer on young adults. *Cancer Med* 2016;5(5):863–870; doi: 10.1002/cam4.657.
- Gordon LG, Merollini KMD, Lowe A, et al. a systematic review of financial toxicity among cancer survivors: We can't pay the co-pay. *Patient* 2017;10(3):295–309; doi: 10.1007/s40271-016-0204-x.
- Thom B, Benedict C, Friedman DN, et al. Economic distress, financial toxicity, and medical cost-coping in young adult cancer survivors during the COVID-19 pandemic: Findings from an online sample. *Cancer* 2021;127(23):4481–4491; doi: 10.1002/cncr.33823.
- Lee M, Lofgren KT, Thomas A, et al. The cost-effectiveness of preimplantation genetic testing for aneuploidy in the United States: An analysis of cost and birth outcomes from 158,665 in vitro fertilization cycles. *Am J Obstet Gynecol* 2021;225(1):55.e1–e55.e17; doi: 10.1016/j.ajog.2021.01.021.
- The Cost of IVF By City. *FertilityIQ*. Available from: <https://www.fertilityiq.com/topics/ivf/the-cost-of-ivf-by-city> [Last accessed: April 28, 2022].
- Lyttle Schumacher B, Grover N, Mesen T, et al. Modeling of live-birth rates and cost-effectiveness of oocyte cryopreservation for cancer patients prior to high- and low-risk gonadotoxic chemotherapy. *Hum Reprod* 2017;32(10):2049–2055; doi: 10.1093/humrep/dex257.
- Family Equality | Average Adoption Costs in the United States. *Family Equality*. Available from: <https://www.familyequality.org/resources/average-adoption-costs-in-the-united-states/> [Last accessed: April 28, 2022].
- Insurance Coverage by State | RESOLVE: The National Infertility Association. Published August 27, 2021. Available from: <https://resolve.org/learn/financial-resources-for-family-building/insurance-coverage/insurance-coverage-by-state/> [Last accessed: April 28, 2022].
- Omesi L, Narayan A, Reinecke J, et al. Financial assistance for fertility preservation among adolescent and young adult cancer patients: A utilization review of the sharing Hope/LIVESTRONG fertility financial assistance program. *J Adolesc Young Adult Oncol* 2019;8(5):554–559; doi: 10.1089/jayao.2018.0151.
- Benedict C, Hahn AL, McCready A, et al. Toward a theoretical understanding of young female cancer survivors' decision-making about family-building post-treatment. *Support Care Cancer* 2020;28(10):4857–4867; doi: 10.1007/s00520-020-05307-1.
- Souza JA de, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). *Cancer* 2017;123(3):476–484; doi: 10.1002/cncr.30369.
- Esselen KM, Gompers A, Hacker MR, et al. Evaluating meaningful levels of financial toxicity in gynecologic cancers. *Int J Gynecol Cancer* 2021;31(6):801–806; doi: 10.1136/ijgc-2021-002475.
- Gorman JR, Su HI, Pierce JP, et al. A multidimensional scale to measure the reproductive concerns of young adult female cancer survivors. *J Cancer Surviv* 2014;8(2):218–228; doi: 10.1007/s11764-013-0333-3.
- O'Connor AM. Validation of a decisional conflict scale. *Med Decis Making* 1995;15(1):25–30; doi: 10.1177/0272989X9501500105.
- O'Connor. User Manual—Decisional Conflict Scale. © 1993 [updated 2010]. Available from: www.ohri.ca/decisionaid [Last accessed: June 8, 2022].
- Decision Self-Efficacy—Evaluation Measures—Patient Decision Aids—Ottawa Hospital Research Institute. https://decisionaid.ohri.ca/eval_self.html [Last accessed: June 12, 2019].
- Benedict C, Thom B, N Friedman D, et al. Young adult female cancer survivors' unmet information needs and reproductive concerns contribute to decisional conflict regarding posttreatment fertility preservation. *Cancer* 2016; 122(13):2101–2109; doi: 10.1002/cncr.29917.
- Gorman JR, Su HI, Roberts SC, et al. Experiencing reproductive concerns as a female cancer survivor is associated with depression. *Cancer* 2015;121(6):935–942; doi: 10.1002/cncr.29133.
- Thom B, Benedict C. The impact of financial toxicity on psychological well-being, coping self-efficacy, and cost-coping behaviors in young adults with cancer. *J Adolesc Young Adult Oncol* 2019;8:236–242; doi: 10.1089/jayao.2018.0143.
- Kaddas HK, Pannier ST, Mann K, et al. Age-related differences in financial toxicity and unmet resource needs among adolescent and young adult cancer patients. *J Adolesc Young Adult Oncol* 2020;9(1):105–110; doi: 10.1089/jayao.2019.0051.
- Ou JY, Waters AR, Kaddas HK, et al. Financial burdens during the COVID-19 pandemic are related to disrupted healthcare utilization among survivors of adolescent and young adult cancers. *J Cancer Surviv* 2022. [Epub ahead of print]; doi: 10.1007/s11764-022-01214-y.

28. Macpherson CF, Johnson RH, Landwehr MS, et al. “Aftermath”: Financial resource requirements of young adults moving forward after cancer treatment. *J Adolesc Young Adult Oncol* 2019;9(3):354–358; doi: 10.1089/jayao.2019.0120.
29. Schmidt R, Richter D, Sender A, et al. Motivations for having children after cancer—A systematic review of the literature. *Eur J Cancer Care (Engl)* 2016;25(1):6–17; doi: 10.1111/ecc.12276.
30. Benedict C, Shuk E, Ford JS. Fertility issues in adolescent and young adult cancer survivors. *J Adolesc Young Adult Oncol* 2016;5(1):48–57; doi: 10.1089/jayao.2015.0024.
31. Logan S, Perz J, Ussher JM, et al. A systematic review of patient oncofertility support needs in reproductive cancer patients aged 14 to 45 years of age. *Psychooncology* 2018; 27(2):401–409; doi: 10.1002/pon.4502.
32. Benedict C, Nieh JL, Hahn AL, et al. “Looking at future cancer survivors, give them a roadmap”: Addressing fertility and family-building topics in post-treatment cancer survivorship care. *Support Care Cancer* 2021;29(4):2203–2213; doi: 10.1007/s00520-020-05731-3.
33. Benedict C, Thom B, Kelvin JF. Young adult female cancer survivors’ decision regret about fertility preservation. *J Adolesc Young Adult Oncol* 2015;4(4):213–218; doi: 10.1089/jayao.2015.0002.
34. Daly C, Micic S, Facey M, et al. A review of factors affecting patient fertility preservation discussions & decision-making from the perspectives of patients and providers. *Eur J Cancer Care (Engl)* 2019;28(1):e12945; doi: 10.1111/ecc.12945.
35. Meernik C, Mersereau JE, Baggett CD, et al. Fertility preservation and financial hardship among adolescent and young adult women with cancer. *Cancer Epidemiol Biomarkers Prev* 2022;31(5):1043–1051; doi: 10.1158/1055-9965.EPI-21-1305.
36. Benedict C, McLeggon JA, Thom B, et al. “Creating a family after battling cancer is exhausting and maddening”: Exploring real-world experiences of young adult cancer survivors seeking financial assistance for family building after treatment. *Psychooncology* 2018;27(12):2829–2839; doi: 10.1002/pon.4898.
37. Mann K, Waters AR, Lopez PLV, et al. Financial burdens of insured adolescent and young adult cancer patients: A need for crowdfunding platforms, fundraisers, financial grants, and cost conversations with their cancer care team. *J Clin Oncol* 2020. [Epub ahead of print]; doi: 10.1200/JCO.2020.38.29_suppl.83.
38. Waters AR, Mann K, Warner EL, et al. “I thought there would be more I understood”: Health insurance literacy among adolescent and young adult cancer survivors. *Support Care Cancer* 2022;30(5):4457–4464; doi: 10.1007/s00520-022-06873-2.
39. Sloan CE, Gutterman S, Davis JK, et al. How can health-care organizations improve cost-of-care conversations? A qualitative exploration of clinicians’ perspectives. *Patient Educ Couns* 2022;105(8):2708–2714; doi: 10.1016/j.pec.2022.04.005.
40. Offodile AC, Gallagher K, Angove R, et al. Financial navigation in cancer care delivery: state of the evidence, opportunities for research, and future directions. *J Clin Oncol* 2022;40(21):2291–2294; doi: 10.1200/JCO.21.02184.
41. Kirubarajan A, Patel P, Leung S, et al. Barriers to fertility care for racial/ethnic minority groups: A qualitative systematic review. *F&S Rev* 2021;2(2):150–159; doi: 10.1016/j.xfnr.2021.01.001.
42. Blanchfield BV, Patterson CJ. Racial and sexual minority women’s receipt of medical assistance to become pregnant. *Health Psychol* 2015;34(6):571–579; doi: 10.1037/hea0000124.
43. Meernik C, Engel SM, Wardell A, et al. Disparities in fertility preservation use among adolescent and young adult women with cancer. *J Cancer Surviv* 2022. [Epub ahead of print]; doi: 10.1007/s11764-022-01187-y.
44. Herndon CN, Anaya Y, Noel M, et al. Outcomes from a university-based low-cost in vitro fertilization program providing access to care for a low-resource socioculturally diverse urban community. *Fertil Steril* 2017;108(4):642–649.e4; doi: 10.1016/j.fertnstert.2017.06.035.
45. Shankaran V. Mitigating the morbidity of financial toxicity in cancer care. *J Adv Pract Oncol* 2021;12(3):271–274; doi: 10.6004/jadpro.2021.12.3.10.
46. Smith GL, Banegas MP, Acquati C, et al. Navigating financial toxicity in patients with cancer: A multidisciplinary management approach. *CA Cancer J Clin* 2022. [Epub ahead of print]; doi: 10.3322/caac.21730.
47. Miller KD, Fidler-Benaoudia M, Keegan TH, et al. Cancer statistics for adolescents and young adults, 2020. *CA Cancer J Clin* 2020;70(6):443–459; doi: 10.3322/caac.21637.
48. Scott AR, Stoltzfus KC, Tchelebi LT, et al. Trends in cancer incidence in US adolescents and young adults, 1973–2015. *JAMA Network Open* 2020;3(12):e2027738; doi: 10.1001/jamanetworkopen.2020.27738.

Address correspondence to:

Catherine Benedict, PhD

Department of Psychiatry and Behavioral Sciences

Stanford University School of Medicine

401 Quarry Road

Stanford, CA 94305

USA

Email: cbenedict@stanford.edu