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TO PRESERVE OR NOT TO PRESERVE: HOW DIFFICULT IS THE DECISION ABOUT FERTILITY PRESERVATION?

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Abstract

Background—The decision to pursue fertility preservation (FP) after a cancer diagnosis is complex. We examined the prevalence of high decisional conflict and specific factors that influence this decision using the decisional conflict scale (DCS).

Methods—The FIRST project is a web-based survey of female cancer survivors (age 18–44 years) who have undergone gonadotoxic treatment. We evaluated the association between recalled decisional conflict and referral to FP counseling, demographic, socioeconomic and cancer variables.

Results—Of 208 participants, 115 subjects (55%) had scores consistent with high decisional conflict (DCS score >37.5 out of 100) and 43 (21%) were in the moderate range (25 – 37.5). In unadjusted analysis, high decisional conflict was associated with lack of referral to FP consultation, not undergoing FP treatment, concerns regarding cost, length of survivorship, lower income, education, partner status and cancer type. In multivariable analysis, significantly higher prevalence of high decisional conflict was observed in participants who were not referred for FP consultation (prevalence ratio [PR] 1.25 (95% confidence interval [CI] 1.06–1.47), as well as in participants who reported cost of FP services to be prohibitive (PR 1.16 (95% CI 1.03–1.31). Prevalence of high DCS was lower for women who underwent FP treatment (PR 0.67 (95% CI 0.52–0.86).

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Precis: This study examined potentially modifiable risk factors associated with decisional conflict related to fertility preservation choices. Increasing fertility preservation consultation referrals and access to treatment may decrease decisional conflict.

Conclusions—In this study of female young adult cancer survivors, the majority recall significant decisional conflict about FP at cancer diagnosis. Increasing access to FP via referral for counseling and cost reduction may decrease decisional conflict about FP for young patients struggling with cancer and fertility decisions.

Keywords

Fertility Preservation; Decisional Conflict; Cancer

Introduction

In an era of increasing survival rates for young cancer patients, there is growing emphasis on post-treatment quality of life¹. For many female young adult survivors, the ability to have biological children is central to their quality of life^{2, 3}. Because many cancer treatments have the potential to be gonadotoxic, newly diagnosed cancer patients are advised to consider their desire for future fertility and fertility preservation (FP) options prior to cancer treatments^{4, 5}. Despite recommendations from the American Society of Clinical Oncology and the American Society of Reproductive Medicine in support of early discussion of treatment-related infertility and referral to a reproductive specialist if desired⁵, very few female young adult patients undergo FP counseling and treatment^{6–8}.

Decisions about undergoing FP counseling and treatment are complex, occurring in a time of turmoil closely following a new cancer diagnosis. There may be a great deal of decisional conflict regarding FP prior to cancer treatment. Factors that may contribute to the stress surrounding FP decisions include unmet information needs on FP options, uncertainty regarding the impact of planned cancer treatment on future reproduction, safety concerns, time constraints and financial considerations⁹. Reproductive specialists are able to provide personalized information about options, risks and financial support resources, provided that newly diagnosed patients are referred appropriately for consultation.

The Decisional Conflict Scale (DCS) is a tool that approximates the degree of uncertainty that individuals encounter when faced with challenging medical decisions^{9–12}. In other medical fields, high DCS scores have been associated with greater emotional distress, delayed decision-making, vacillation between decisions, future regret, and placement of blame on providers^{13, 14}. Recent research with female young adult cancer survivors indicates high decisional conflict associated with FP decisions^{15, 16}.

The goal of this study is to identify factors associated with decisional conflict about FP using data from a prospective cohort study of reproductive outcomes in female young adult cancer survivors. We hypothesized that the majority of female cancer survivors would report experiencing high decisional conflict with regard to decisions about FP prior to cancer treatment. As decisional conflict may result from unmet informational needs, we further hypothesized that referrals to FP consultation would be associated with decreased decisional conflict.

Materials and Methods

The Fertility Information Research Study (FIRST) is an ongoing prospective cohort study examining reproductive outcomes in female young adult cancer survivors. Inclusion criteria for the FIRST project are women age 18 to 44 years at study enrollment with a personal history of cancer. We conducted a cross-sectional study approved by the institutional review board at the University of California, San Diego using FIRST data. For this analysis, we included FIRST participants who underwent potentially gonadotoxic cancer therapy

including systemic chemotherapy, pelvic radiation and/or gynecological surgery. FIRST participants were recruited from social media outreach through young adult cancer survivor advocacy groups, six university-based fertility preservation programs, and other sources including patient referrals. Participants were recruited from 44 states in the U.S. and completed the enrollment telephone- or web-based questionnaire between May, 2011 and October, 2012. The study questionnaire included questions on demographic, cancer, medical, and reproductive history, and recalled decision conflict about fertility preservation. Subjects were asked if they felt that FP consultation and/or treatment was cost prohibitive. Subjects reported if they had been referred for a FP consultation and whether they underwent any FP treatments including: GnRH agonists such as GnRH agonists, embryo banking, egg banking, surgical oophorectomy or other.

Decisional Conflict

Decisional conflict was assessed using a modified version of the validated DCS¹⁷. This tool included 16 items, each using a five-point Likert response format. Final scores range from 0 (low decisional conflict) to 100 (high decisional conflict). Scores > 37.5 indicate high levels of decisional conflict, scores 25 – 37.5 represent a moderate degree of conflict, while scores < 25 indicate confidence in decisions made¹⁷. Study participants were asked to ‘think about the choice they made about fertility preservation’ when answering the DCS items.

Statistical Analysis

Descriptive statistics were calculated as frequencies and percentages for categorical data and median and interquartile ranges (IQR) for continuous data. We used Wilcoxon Rank Sum tests to evaluate differences in DCS scores by demographic, cancer, and FP referral and treatment characteristics. A Pearson Correlation coefficient was used to evaluate the correlation between time since cancer diagnosis and DCS. Because of the high prevalence of DCS > 37.5 in the cohort, log-binomial regression was used to estimate unadjusted prevalence ratios (PR) and 95% confidence intervals (95% CI) for high DCS, as well as those adjusted for potential confounding factors¹⁸. We developed three separate multivariable models to examine the association between the outcome variable, high DCS about fertility preservation, and three explanatory variables: 1) referral for FP consultation; 2) uptake of FP treatment; and 3) cost concerns related to FP services (consultation or treatment). Because of the likely causal influences of FP consultation and cost concerns on uptake of treatment, and in order to avoid over-adjustment¹⁹ or induced bias²⁰, we modeled these variables separately. We included potential confounders, variables that were significantly associated with the outcome and explanatory variable, in each model. Additionally, a sensitivity analysis to assess potential recall bias was performed by evaluating unadjusted models in subsets of the data defined by the time between cancer diagnosis and completing the survey. Statistical analyses were conducted using SAS statistical software v9.2 (Cary, NC).

Results

Of 237 FIRST participants, 29 were excluded because they did not receive gonadotoxic therapy, leaving 208 for analysis. Table 1 summarizes participant characteristics. Median age of participants was 31 years (IQR 26–35 years). Breast cancer was the most common cancer type. Few participants (6.3%) reported having no form of health insurance.

One hundred three participants (49.5%) reported referral for fertility preservation consultation. Sixty-four percent of these participants were referred by their primary oncologist, while the remainder was referred by other physicians or were self-referred. Eighty-five women (41%) underwent FP treatment including egg, embryo, or ovarian tissue

banking, or treatment with GnRH agonist. The median DCS score of the study population was 41.1 (IQR 25.0 – 57.0). One hundred fifteen participants (55.3%) had scores consistent with high decisional conflict (>37.5 out of 100).

Table 2 demonstrates univariate associations with DCS scores. Participants who were not referred to FP consultation had significantly higher DCS scores compared to women who were referred (51.6 [IQR 37.5–64.1] vs. 31.3 [IQR 18.8–43.8]; $P<0.0001$). DCS scores were lower in those who underwent FP treatment ($P<0.0001$). Participants who reported lower income, lower level of education completed, and not being in a partnered relationship had higher decisional conflict. Compared to survivors of breast cancer, women reporting other cancers had higher DCS scores. Longer time since diagnosis was also correlated with higher scores ($\rho=0.35$, $P<0.0001$). Subjects who were more than 5 years after cancer were nearly twice as likely to recall high DCS than women in the first year of survivorship. Age, race, parity and desire for future fertility were not significantly associated with DCS scores.

Associations between income, education, relationship status, cancer type and each of the FP explanatory variables were examined. Income was related to both cost concerns and FP treatment; those with income <\$50K were twice as likely to report cost concerns (52% vs. 25%, $P<0.0001$) and roughly half as likely to have FP treatments, compared to those not reporting incomes <\$50K (23% vs. 41%, $P=0.007$). Education was unrelated to any of the FP variables of interest. Relationship status was related to cost concerns and referral for counseling but not treatment. Those reporting being partnered were less likely to report cost concerns (42% vs. 66%, $P=0.001$) and more likely to be referred for consultation (61% vs. 54%, $P<0.0001$) than those reporting not being partnered. While cancer type was not associated with cost concerns or FP treatment, participants with breast cancer were more likely to be referred for consultation than those with other cancers (66% vs. 23%, $P=0.001$).

Table 3 depicts both models of high DCS adjusted only for time since diagnosis and for models adjusting for confounding factors in addition to time since diagnosis. In models of high DCS adjusted only for time since diagnosis, non-referral was associated with a nearly two-fold increased likelihood of high DCS (PR 1.83, $P<0.0001$). Undergoing FP treatment was associated with significantly lower likelihood of high DCS (PR 0.53, $P<0.0001$). Reported cost concerns was also associated with high DCS (PR 1.23, $P=0.006$).

In models adjusting for potential confounding factors and time since diagnosis, estimates for each of the FP explanatory variables were attenuated, but remained statistically significant (Table 3). Women who were not referred to FP consultations were significantly more likely to report high decisional conflict (PR 1.25, $P=0.009$). Those who underwent FP treatment were less likely to have high decisional conflict (PR 0.67, $P=0.001$). Finally, women who felt FP consultation or treatment was cost prohibitive reported more decisional conflict in these adjusted analyses (PR 1.16, $P=0.01$). In all adjusted models, income, partner status, time since diagnosis, and cancer type were no longer significantly associated with high decisional conflict.

Results of a sensitivity analysis to assess potential effects of time since diagnosis as a potential source of recall bias on estimates are shown in Table 4. For this assessment, unadjusted models of high DCS were run to assess associations with non-referral for FP consultation, uptake of FP treatment and cost concerns in the entire cohort ($n=208$), in the subset who completed the survey within 3 years of diagnosis ($n=123$) and in the subset who completed the survey within 1 year of diagnosis ($n=47$). Estimates were similar across these subsets for all three variables considered.

Discussion

In this study, we examine decisional conflict regarding fertility preservation prior to cancer treatment in a cohort of female young adult cancer survivors. As hypothesized, the study found that the majority of women recalled moderate to high decisional conflict about their FP decisions prior to gonadotoxic cancer treatment. Young women who were not referred to FP counseling or for whom cost of either counseling or treatment was prohibitive experienced significantly higher rates of decisional conflict. These results identify modifiable factors that could reduce decisional conflict and improve care of female young adult cancer patients.

Decisional conflict is a state of uncertainty about the course of action to take. Increased decisional conflict may result from making choices that have high stakes in terms of risks and rewards, ones that are rushed or have time limits, that encompass moral judgments and have uncertainty of outcomes and when there may be anticipated regret about the positive aspects of rejected options¹⁷. The decision to pursue FP services prior to cancer treatment involves many of these qualities and is extremely time sensitive. Concordantly, in this study, a large portion of reproductive aged women recalled having had moderate (21%) to severe (55%) conflict about their FP decisions.

These findings are consistent with the limited data on decisional conflict in female cancer patients regarding fertility interventions. In a decision aid intervention study in newly diagnosed young breast cancer patients, mean DCS scores on fertility intervention reported at diagnosis was 48.3, with 63% of participants reporting high decisional conflict¹⁶. Follow up of this cohort demonstrated lower DCS scores at 12 months, even in those who did not receive the decision aid intervention (mean DCS score 29.3 without intervention versus 14.7 with intervention)²¹. In the current study, high DCS scores (median 41.4) were recalled by survivors of a variety of common YA cancers (breast cancer constituted 32% of the cohort), even at an average of 2.4 years after diagnosis. These results highlight the challenges faced by female young adult cancer patients regarding FP decisions at cancer diagnosis.

In multivariate analyses, we found three factors associated with increased decisional conflict: lack of referral to FP consultation, concerns that FP services were cost prohibitive, and not undergoing fertility preservation treatment. During consultations, reproductive specialists aim to provide in depth counseling on not only FP procedures, but also risks to long-term reproductive health associated with cancer treatment. In this cohort, FP consultation referral was associated with less decisional conflict. This is consistent with studies suggesting that without specialized FP counseling, comprehension of FP options may be compromised, and that more patients may be interested in FP treatment if knowledge was increased^{16, 22}. Moreover, in a recent web-based survey completed by female cancer survivors who had undergone FP consultation, the median DCS was 29.7, which is similar to the scores in the current study among women who had undergone FP counseling (31.3)¹⁵. Finally, data support that discussion of FP options alone, even if patients do not undergo FP treatment, may allow patients to feel more comfortable with their decisions and future fertility outcomes. Counseling may facilitate educated decisions as well as provide an opportunity for patients to cope with potential treatment-related infertility and for providers to manage expectations²³.

Currently, most specialized FP counseling occurs by consultations with reproductive specialists. However, the emergence of trained patient navigators and decision aids to inform decisions about FP at the time of cancer diagnosis may offer an alternative, more cost-effective approach to delivering FP information¹⁶. As these services are developed, it is pertinent to note we found higher decisional conflict in participants with lower income and

less formal education. This finding highlights the potential relationship between health literacy levels and FP decision-making. Effective educational strategies will need to be developed to adequately address needs of diverse populations.

One-third of participants reported that costs for FP services were prohibitive, and those for whom costs were prohibitive experienced higher decisional conflict. Cost as a barrier to FP treatment has remained a prominent issue as FP awareness has increased but insurance coverage for FP treatments remains severely limited. In a recent multi-institutional study examining decisional conflict after FP counseling, 41% of female survivors stated that ‘cost’ was the most influential factor in their decision making²². Improving access and financial support for FP is modifiable and continues to evolve at the organizational (Livestrong Sharing Hope Program, Ferring heartbeat program) and state health policy levels.

Finally, interestingly, higher decisional conflict on FP was observed in women with longer durations of survivorship, a finding opposite of those of Peate and colleagues¹⁶. We speculate that this finding may reflect priorities shifting from cancer treatment to survivorship and stronger consideration of adverse late effects as participants recall the decisions they made on FP. However, further longitudinal studies are needed to validate this finding.

Strengths of this study include a moderately large, geographically diverse sample of female young adult cancer survivors and ascertainment of FP outcomes. This study also utilized recruitment through social media outreach to reach a unique subset of survivors that may not have otherwise been represented. This study is also the largest to date to assess decisional conflict related to FP choices and to investigate modifiable factors to decrease that conflict.

This study has several limitations. Patients self-selected to be part of the FIRST project and may have done so because they had especially positive or negative feelings regarding their FP choices. Moreover, participants tended to be Caucasian, report moderate to high income, and were highly educated – these characteristics need to be taken into account when considering the generalizability of the study. Our results suggest that young survivors who undergo FP treatment have lower decisional conflict than those who do not. While reassuring, this cross-sectional study design limits our ability to make causal inferences. This finding may also represent a recall bias, where those who underwent FP treatment recalled conflict regarding FP treatment decisions differently than those who did not undergo treatment. Because decisional conflict was assessed after decisions were made, and possibly after the reproductive outcome of gonadotoxic treatment was known, it is possible that satisfaction with either undergoing FP treatment or post-treatment fertility influenced their recalled decisional conflict. It is reassuring that in sensitivity analysis, we found similar magnitudes of association between high decisional conflict and FP variables across duration of survivorship. However, prospective studies in a diverse group of female young adult cancer patients from diagnosis forward are needed to assess decisional conflict longitudinally.

The majority of female young adult cancer survivors in this study recalled significant decisional conflict related to their decisions about FP at the time of their cancer diagnosis. As many young patients will be at risk of loss of fertility with cancer treatment, it is critical to identify modifiable risk factors associated with decisional conflict to inform the design of effective interventions to improve quality of care and to optimize fertility and parenthood options for young survivors.

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Table 1

Characteristics of FIRST participants (n=208)

	Median (IQR) or N (%)
Age (years) (n=207)	31.0 (26.0–35.0)
Race (n=205):	
Caucasian	161 (78.5%)
African American	6 (2.9%)
Asian	11 (5.4%)
Other	27 (13.0%)
Income:	
<\$50,000	71 (34.2%)
\$50,000	90 (43.3%)
Declined to answer	47 (22.6%)
Education: < college	39 (18.7%)
Partnered relationship status	120 (57.7%)
Nulliparous	132 (63.5%)
Desire for future fertility	168 (80.8%)
Cancer type:	
Breast	67 (32.2%)
Hodgkin's Lymphoma	41 (19.7%)
Gynecologic (cervix, ovary, uterine)	23 (11.1%)
Non-Hodgkin's Lymphoma	21 (10.1%)
Leukemia	16 (7.7%)
Other	40 (19.2%)
Years since cancer diagnosis (n=207)	2.44 (1.10–5.08)
No referral for FP consultation	105 (50.5%)
Underwent FP treatment	85 (40.9%)
Cost prohibitive:	
FP consultation	64 (30.8%)
FP treatment	60 (28.8%)
FP services (consultation or treatment)	71 (34.1%)
Recruitment source:	
Social media	119 (57.2%)
Clinic-based	56 (26.9%)
Other	33 (15.9%)
DCS score	41.4 (25.0 – 57.0)

	Median (IQR) or N (%)
Low (< 25)	50 (24.0%)
Moderate (25 – 37.5)	43 (20.7%)
High (> 37.5)	115 (55.3%)

Legend: IQR – interquartile range; FP – fertility preservation; DCS – decisional conflict scale

Table 2

Median decisional conflict scale scores by demographic and clinical characteristics

	Variable present	Variable absent	P-Value ²
Age >30 years	37.5	45.3	0.09
Race: Caucasian	42.2	37.5	0.39
Income <\$50,000 ¹	53.1	35.9	0.002
Education < college	50.0	39.1	0.02
Partnered relationship status	35.9	50.0	0.01
Nulliparous	40.6	43.0	0.91
Desire for future fertility	40.6	50.0	0.10
Cancer type: Breast	35.9	45.3	0.01
No referral for FP consultation	51.6	31.3	< 0.0001
Underwent FP treatment	26.6	50.0	< 0.0001
FP services cost prohibitive ³	56.3	32.8	<0.0001

Legend: DCS – decisional conflict scale; FP – fertility preservation

¹ Income was analyzed as a three level variable (‘ \$50,000’, ‘<\$50,000’, or ‘declined to answer’). Only the comparison of ‘<\$50,000’ compared to ‘ \$50,000’ is shown in the table. No difference was seen between ‘decline to answer’ and the reference level of ‘ \$50,000’ (p=0.34)

² Wilcoxon Rank-Sum test

³ Includes FP consultation and/or treatment

Table 3

Prevalence ratios (95% CI) from models of high decisional conflict (DCS Score > 37.5) adjusted for time since diagnosis and for demographic risk factors (fully adjusted) (n=208)

	Time since diagnosis adjusted	Fully adjusted ¹		
		No referral for FP consultation	Underwent FP treatment	FP services cost prohibitive
FP variables				
No referral for FP consultation	1.83 (1.37, 2.44)	1.25 (1.06 – 1.47)	-	-
Underwent FP treatment	0.53 (0.39, 0.71)	-	0.67 (0.52 – 0.86)	-
FP services cost prohibitive ³	1.23 (1.09, 1.38)	-	-	1.16 (1.03 – 1.31)
Demographic variables				
Income < \$50,000 ²	1.40 (1.13, 1.75)	1.14 (0.95 – 1.37)	1.12 (0.89 – 1.40)	1.05 (0.91 – 1.23)
Partnered relationship status	0.76 (0.62, 0.93)	0.93 (0.81 – 1.07)	0.90 (0.75 – 1.07)	0.97 (0.87 – 1.09)
Cancer type: Breast	0.79 (0.57, 1.08)	0.98 (0.81 – 1.19)	0.93 (0.73 – 1.18)	0.95 (0.82 – 1.09)

Legend: DCS – decisional conflict scale; FP– fertility preservation

¹ Fully adjusted models included the FP variable, income, relationship status, cancer type and log-transformed time since diagnosis

² Income was analyzed as a three level variable (' \$50,000', '<\$50,000', or 'decline to answer'). The PR for 'decline to answer' compared to the reference level of ' \$50,000' was approximately equal to 1 and not statistically significantly different

³ Includes FP consultation and/or treatment

Associations with prevalence of high decisional conflict (DCS Score >37.5) grouped by time since completing the survey; estimates in the full FIRST cohort (n=208), those within 3 years of survivorship (n=123) and those within 1 year of survivorship (n=47).

Table 4

	Prevalence ratios from models of high DCS by time in survivorship					
	Full cohort (n=208)		Within 3 rd year of survivorship (n=123)		Within 1 st year of survivorship (n=47)	
	PR	95%CI	PR	95%CI	PR	95%CI
No referral for FP consultation	2.07	(1.56, 2.74)**	2.07	(1.42, 3.02)**	2.62	(1.44, 4.76)**
Underwent FP treatment	0.42	(0.30, 0.59)**	0.41	(0.26, 0.65)**	0.40	(0.20, 0.81)*
FP services cost prohibitive	1.96	(1.56, 2.46)**	2.64	(1.84, 3.78)**	2.36	(1.28, 4.36)*

Legend: DCS – decisional conflict scale; FP – fertility preservation

* P 0.01,
** P 0.001