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Applying behavioral theory to understand fertility consultation uptake after cancer

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Abstract

Objective—The objective of this study was to examine the association between theoretical constructs from the Health Belief Model and fertility consultation status after cancer.

Methods—Reproductive-aged female cancer survivors self-reported their use of fertility consultation, perceived severity of and susceptibility to infertility, perceived barriers to and effectiveness of fertility consultation, and cues to action from family/peers and doctors, as well as demographics and cancer characteristics. Logistic regression was used to analyze the association between theoretical constructs and fertility consultation status.

Results—Fertility consultation uptake was more prevalent among survivors with higher incomes, those without children, those who wanted a (another) child, and those who were diagnosed more recently. In the final multivariate model, higher perceived severity of infertility, fewer perceived barriers to fertility consultation, and more cues to action from family/peers and doctors were significantly associated with fertility consultation uptake, controlling for income. Exploratory bivariate analyses of barriers to fertility consultation revealed that cost and trouble accessing services were significantly associated with not having a fertility consultation.

Conclusions—The Health Belief Model is useful for understanding factors associated with fertility consultation uptake. Efforts should be made to reduce financial barriers and improve patient-centered assessment of family building goals.

Keywords

cancer; oncology; fertility; counseling; fertility preservation; reproductive health; theory

BACKGROUND

According to guidelines set by the American Society of Clinical Oncology, a discussion of the risk of infertility is indicated for all cancer patients of reproductive age as early as

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possible before cancer treatment starts.¹ Those who are interested should be referred by their oncology team to a fertility specialist to discuss fertility preservation (FP) options. Patients who expect to undergo gonadotoxic therapy have a short window of time between cancer diagnosis and starting treatment to be informed about FP options, make informed decisions, and pursue FP, if biological parenthood is desired. However, oncofertility care is currently not being delivered to all eligible patients or to the standard of the clinical guidelines that are in place,^{2, 3} and survivors continue to report unmet information needs, decision regret, and decision conflict about FP.⁴⁻⁶

Discussions about infertility risk are an important aspect of high quality of cancer care for reproductive-aged patients.⁷ While oncology teams are initiating discussions of fertility about half of the time,⁷ rates of fertility consultation with reproductive specialists (FC) prior to cancer treatment remain inadequate, with estimates ranging from 5 to 26%.⁸⁻¹¹ Barriers to FC include treatment-related time constraints, high cost, patient characteristics (e.g., socioeconomic status, partner status) that can influence provider discussions of fertility, lack of provider training, lack of access to care, and lack of knowledge or information.^{8, 12-15} FC most often occurs at the time of cancer diagnosis, when patients have more FP options available to them, but can also be beneficial later in survivorship. The benefits of FC after completing treatment include discussing alternative family building options, such as adoption, as well as ovarian reserve monitoring and earlier or more aggressive fertility treatments to help women achieve their goals within a narrower window of opportunity for having biological children.¹⁶ However, FC uptake is also markedly low among cancer survivors after completing their cancer treatment.^{16, 17}

In a sample of young adult female cancer survivors, women not referred to a fertility specialist for FC experienced significantly higher decisional conflict regarding FP compared to those who were referred.¹⁸ Similarly, in a sample of young adult female survivors who had completed cancer treatment and were interested in possibly having children, those with lower knowledge about their risks of premature menopause and family building options experienced higher levels of decisional conflict about FP.¹⁷ Women who received FC experience reduced long-term regret concerning fertility choices, improved physical quality-of-life (QOL) scores, and a trend toward improved psychological QOL scores compared to women who did not receive a FC.⁴ They also report that the possibility of preserving fertility was instrumental in helping them cope and experience greater satisfaction even if they did not pursue FP options.^{4, 19}

Prior studies have pointed to characteristics associated with having consultation with a fertility specialist, including higher socioeconomic status, but have detailed little about how individual cognitive factors are related. In the present study, the Health Belief Model (HBM)^{20, 21} provided an a priori framework to increase our knowledge of how personal beliefs and perceptions are associated with FC uptake. The HBM is one of the mostly widely recognized theories in the field of health promotion, and has been demonstrated to help explain a range of health behaviors.²² In the context of this study, HBM's key constructs include perceived risk and severity of infertility, perceived benefits of and barriers to FC, and cues from healthcare providers and friends/family that prompt FC uptake. The primary objective of this cross-sectional study was to determine the association between these HBM

constructs and FC uptake after cancer diagnosis. Secondly, we evaluated the differences between reproductive-aged female cancer survivors who had FC after cancer compared to those who did not. Identifying cognitive factors associated with FC uptake may be useful in planning interventions that encourage FC across the cancer care continuum and identifying target populations who would benefit.

METHODS

Participants

Participants enrolled in the Fertility Information Research Study (NCT01843140), a prospective cohort survey study, between May 2011 and February 2013. We recruited participants through referrals from diverse sources including social media outreach, university-based fertility preservation programs, FERTLINE (the Oncofertility Consortium's telephone hotline), community outreach, or word of mouth.²³ Eligible participants were between the ages of 18 and 44 years, female, and had a past cancer diagnosis. Participants had variable durations of cancer survivorship; eligibility was not restricted by time since diagnosis or treatment. The current analysis uses data collected during the first follow-up questionnaire of 239 participants (71.5% of total enrolled at baseline), where the mean duration of survivorship was 5 years. The institutional review board at University of California, San Diego approved this study (Protocol #110343).

Measurement

We obtained self-report data on demographics and cancer characteristics, including diagnosis and type of treatment received. We assessed reproductive history and desire for children using standard questions from the National Survey for Family Growth.²⁴ We used the time to pregnancy assessment²⁵ and the Penn Ovarian Aging Study Menstrual Questionnaire²⁶ to measure infertility and menstrual patterns.

The primary dependent variable, FC uptake, was assessed with the question: "After your cancer diagnosis, did you ever have a fertility consultation with a reproductive specialist (also called a fertility specialist or reproductive endocrinologist)?" Those who said "yes" were compared to those who said "no" or "not sure". Participants reported whether their consultation occurred before or after their cancer treatment. We explored FC at any time point in the cancer care continuum because women's fertility and family building needs do not end after cancer treatment begins.

Constructs from the health belief model (HBM) were assessed with a series of investigator-developed items based on prior research.²⁷ Theoretical constructs from the HBM were measured by 12 questions to assess perceived susceptibility, perceived severity, barriers, effectiveness, and cues to action. For most constructs, the response options were "strongly disagree", "disagree", "neither agree nor disagree", "agree", or "strongly agree" (coded 1–5). For perceived susceptibility, response options were "very unlikely", "somewhat unlikely", "somewhat likely", and "very likely". When multiple items measured a construct, we calculated mean scores and Cronbach's alpha to assess internal consistency. In all cases, higher values indicate greater endorsement of the construct (Table 1).

Statistical Analysis

We compared demographics, reproductive history, and cancer characteristics by FC status using ANOVA, chi-square tests, and Fisher's exact test as appropriate. We calculated raw mean scores of each individual theoretical construct domain from the HBM by FC status. We then developed logistic regression models to determine the association between theoretical construct domains and FC status. We conducted multiple regression using the logit model, and based on the theoretical framework of the measured HBM constructs. In Model 1, we used simultaneous regression based on the a priori theoretical frameworks of six HBM domains. In Model 2, we used forward selection stepwise logistic regression to develop the most parsimonious model predicting FC. In this model, we added each construct of the HBM and covariates in a stepwise fashion, retaining only those with $p < 0.05$. Covariates were selected based on their theoretical relevance to FC uptake and included participant age, time since diagnosis, partner status, income, having at least one child, and wanting a (another) baby. In descriptive bivariate analyses, we calculated the raw mean scores for each item representing the barrier construct and evaluated the correlation between these scores and FC status using t-tests. We analyzed data in SAS using two-tailed tests (critical $\alpha < 0.05$).

RESULTS

Participant Characteristics

Table 2 depicts demographic and cancer characteristics of participants. The mean age (standard deviation, SD) of participants was 32.8 (5.8) years. The majority of participants were white (80%), college graduates (89%), and had health insurance (95%). The two most common cancer types in our cohort were breast cancer (28%) and lymphoma (26%). Mean age at the time of cancer diagnosis was 27.3 (7.2) years. The present sample was similar to the 334 participants originally enrolled across all baseline characteristics except one: participants in the present sample were more likely to have at least one child.

Fertility consultation uptake

Overall, 52% of the sample ($n=124$) reported ever having had FC. Of those, 73% had their first consultation before or during their cancer treatment, and 27% had a consultation only after their cancer treatment. Comparing those who did and did not have FC, those who had a consultation were more likely to be in the highest income group ($p = .04$) and to not have a biological child ($p = .04$) than those who did not have a consultation. Those who had a consultation were also more likely to report wanting a baby ($p < .001$) than those who did not have a consultation. Additionally, those who had a consultation were diagnosed more recently than those who did not have a consultation ($p = .02$). There were no statistically significant differences across the other characteristics by consultation status (Table 2). We also compared the characteristics of the subgroup of participants who had FC before their cancer treatment compared to those who had a consultation afterward (Appendix, Supplemental Table 1).

Health Belief Model constructs

In bivariate analyses, higher perceived severity of infertility (OR 1.77, 95% CI 1.38–2.28), lower perceived barriers to FC (OR 0.52, 95% CI 0.36–0.76), and higher perceived effectiveness of FC (OR 1.86, 95% CI 1.36–2.53) were associated with having FC. Those who received a recommendation for FC from a healthcare provider (OR 6.69, 95% CI 3.78–11.84) and those who had talked with their family and friends about FC (OR 6.85, 95% CI 3.88–12.08) had higher odds of FC. The results were in the expected direction and consistent with the Health Belief Model (Table 3).

Similarly, in multivariable logistic regression model simultaneously controlling for the measured HBM constructs (Model 1, Table 3), higher perceived severity of infertility (OR 1.70, 95% CI 1.25–2.30) and lower perceived barriers to FC (OR 0.40, 95% CI 0.25–0.64), were associated with having FC. Additionally, those who reported that they received a recommendation from a healthcare provider (OR 3.91, 95% CI 1.98–7.73) or talked to a family member and friend about FC (OR 4.09, 95% CI 2.02–8.27) had higher odds of FC. Neither perceived susceptibility to infertility nor perceived effectiveness of FC were significantly associated with FC uptake (Model 2, Table 3). Adding participant age, time since diagnosis, partner status, income, having at least one child, and wanting a (another) baby did not change the statistical significance of any variables in Model 1 or Model 2. Income was the only significant covariate in Model 2, thus it was retained in the model. Although we did not have sufficient statistical power because of the small sample size, we also evaluated the potential role of the timing of FC (before vs. after cancer treatment) and found no evidence of effect modification.

In exploratory bivariate analyses evaluating possible barriers to FC, three of the five items measuring barriers were associated with lower FC uptake ($p < 0.05$). Mean scores were higher for the items assessing “too much trouble” and “too expensive” for those who reported no FC compared to those who did have a consultation. Mean scores were lower for the item “Having a fertility consultation would force me to make difficult decisions” for those who reported no FC compared to those who did have a consultation (Table 4).

CONCLUSIONS

This is the first quantitative study focused of fertility care after cancer to use an a priori theoretical framework to determine the relationship between key constructs of the theory (HBM) and FC uptake. We found that women who perceived that infertility would incur significant emotional distress were less likely to have had FC. Cues to action from family, friends, and doctors were associated with higher FC uptake, but there are still major obstacles that prevent survivors from accessing FC after cancer, particularly financial and access barriers.

Although HBM has been demonstrated to help explain a range of health behaviors,²² it has not previously been used as a framework for research focused on understanding uptake of FC among cancer survivors. Within the field of health promotion, theory is a tool to help us understand complex situations, and a cornerstone of intervention development. To date, only a small number of qualitative studies have used a theoretical framework to guide research

questions about uptake and experience with FP.^{28, 29} Additional qualitative and quantitative studies guided by a theoretical framework would enhance our knowledge of women's uptake of and experiences with FC and FP, as well as provide insight on effective approaches to improve access to and quality of care.

Despite the fact that 72% of participants reported wanting to have a (another) child, only 52% (n=124) of them reported accessing FC services at any time after their cancer diagnosis. However, it is important to note that this is not a population-based sample, and that FC uptake rates were higher in this study than rates reported in other studies (5–26%).^{8–11} The characteristics of participants who utilized FC were similar to those described in a systematic review, which reported that across several studies, more than 75% of patients who utilized FC were white women, two-thirds were either married or in long-term relationships, and two-thirds did not have a previous biological child.⁴ Another study reported similar demographics for patients who received FC: 80% wished to conceive, 87% were nulliparous, and 84% were partnered.³⁰ We did not identify significant differences between survivors who did and did not utilize FC across race, ethnicity, or partner status, however, those who utilized FC were more likely to have a higher income, be more recently diagnosed, not have a biological child, and want a baby. Additional population-based studies are needed to identify characteristics of survivors who utilize FC across the cancer care continuum compared to those who do not, and the reasons why. This information would support the ongoing international efforts toward integrated, long-term oncofertility care for reproductive-aged survivors across the cancer care continuum.

Consistent with commonly cited barriers to fertility consultation and preservation,^{8, 12–15} our results highlight the importance of perceived barriers related to access. Study participants who did not utilize FC were more likely to report that it was “too expensive” or “too much trouble”. This was also represented in bivariate analyses, where only 40% of participants in the lower income group reported FC uptake compared to 58% in the higher income group. Additionally, income remained as a significant covariate in the final multivariate model. Financial burden faced by young adult cancer survivors can be tremendous,^{31, 32} and is associated with worry about achieving parenthood goals, which may require additional expenses (i.e., via adoption or assisted reproductive technology).^{12, 33} Access and financial barriers to FC and FP exist globally. Addressing these barriers through policy changes, such as recent state mandates for insurance coverage of FP for oncology patients, is needed to improve FC and FP uptake.

Not surprisingly, those who had received FC reported higher perceived severity of infertility (i.e., it would be emotionally difficult), suggesting that those who highly value parenthood are more likely to pursue FC, despite facing barriers such as financial cost. We also found that survivors' healthcare providers and family/friends were influential in FC uptake. This is consistent with studies of other health decisions where patients experience barriers, such as vaccination, where healthcare provider recommendations are persuasive in changing behavior.^{34, 35} It also reinforces the importance of continued efforts to educate healthcare providers in an effort to improve patient-provider communication about fertility and referral to fertility specialists.³⁶ Partners, other family members, and friends are often engaged in cancer care decisions and caregiving, and may offer an avenue for sharing information to

facilitate informed decisions about FC. Following a patient-centered care model,³⁷ engaging family/friends in conversations and care decisions is an important aspect of care. Interestingly, neither perceived effectiveness of FC nor perceived susceptibility to infertility were significantly associated with FC in multivariate models, suggesting that other factors held more influence.

Study Limitations

Because many participants chose to participate in a fertility-focused research study, and some were recruited from fertility preservation programs, they were likely to have been more motivated to pursue FC than other female cancer survivors. The FC uptake rates in this sample were notably higher than those reported in prior studies. This limits the generalizability of our results. The cross-sectional design where women reported on FC at any time after their diagnosis, and their current feelings about FC, limits our ability to make causal inferences. Longitudinal studies are needed to determine factors influencing FC at the time of diagnosis and at later times in survivorship, as feelings toward childbearing and life circumstances can change over time. Finally, it is possible that some women did not recall having a fertility consultation, leading to underreporting. We did not have access to medical record data to confirm self-reports.

Clinical Implications

Study participants were diagnosed an average of 5 years prior to this study and, of those wanting a baby, 60% had not accessed FC at any point after their diagnosis. This study provides insight into why that might be. FC was more common among those who felt that having children was an important part of their life plan and those who reported fewer barriers. The most significant barriers related to finances and trouble accessing services. Improving access for all cancer survivors who desire children, including by reducing financial burden, could help reduce future distress related to unmet family building goals.^{38–40} Other independent predictors of FC uptake were cues to action via recommendations from a healthcare provider or discussions with friends and family. Efforts to reduce financial barriers and improve patient-centered assessment of family building goals and values across the cancer care continuum hold promise for improving access to FC services. This could include routine assessment of desire for children in survivorship, and increasing survivor and partner/family member knowledge about how and when to access fertility counseling and cost estimates for fertility consultation and services, in addition to ongoing efforts to improve insurance coverage.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Assessment of theoretical constructs

Health Belief Model		Cronbach's alpha
Perceived susceptibility to infertility	Without a fertility consultation, what do you think is the chance that you could not become a parent someday?	-
Perceived severity of infertility	It would be emotionally difficult for me if I was not able to become a parent someday. My whole life plan would change if I was not able to become a parent someday.	0.81
Barriers related to fertility consultation	I haven't been feeling well enough to have a fertility consultation. Having a fertility consultation would force me to make difficult decisions. It is too much trouble to have a fertility consultation. Having a fertility consultation is too expensive. I'm afraid that if I have a fertility consultation I might find out bad news.	0.66
Effectiveness of fertility consultation	Having a fertility consultation would help me to become a parent in the future. Having a fertility consultation would provide information to help me plan for the future.	0.83
Cues to action from family or friend ^a	People who are important to me, such as my family and friends, have talked with me about having a fertility consultation.	-
Cues to action from doctor ^a	My doctor recommended that I have a fertility consultation during an office visit, on a telephone call, or by sending me a letter.	-

^aItem dichotomized (never vs. one or more times) for analysis.

Table 2.

Respondent characteristics by fertility consultation after cancer status (unadjusted analyses) (N=239)

	No fertility consultation (n= 115) n (%)	Fertility consultation after cancer (n=124) n (%)	p
Demographics			
Age (mean, SD)	32.26 (5.98)	33.28 (5.63)	0.17
Non-Hispanic White	93 (80.87)	91 (73.39)	0.09
Hispanic	7 (6.09)	13 (10.48)	0.25
Partnered	67 (58.26)	81 (65.32)	0.26
Income			
<= \$50,000	45 (39.13)	30 (24.19)	0.04
> \$50,000	61 (53.04)	83 (66.94)	
Prefer not to answer	9 (7.83)	11 (8.87)	
Employment Status			
Full Time	63 (55.26)	72 (58.54)	0.81
Part Time	19 (16.67)	21 (17.07)	
Other	32 (28.07)	30 (24.39)	
College graduate	98 (87.5)	110 (90.16)	0.52
Reproductive History			
Has at least one child	40 (34.78)	28 (22.58)	0.04
Ever pregnant before cancer	30 (26.09)	23 (18.55)	0.16
Ever pregnant after cancer	23 (20.0)	26 (21.77)	0.74
Wants a (another) baby			
No / Not Sure	46 (40.0)	21 (16.94)	< 0.001
Yes	69 (60.0)	103 (83.06)	
Cancer Characteristics			
Life stage at diagnosis			
Childhood (14)	8 (6.96)	3 (2.42)	0.19
Adolescence (15–19)	14 (12.17)	12 (9.68)	
Young Adult/Adult (20–44)	93 (80.87)	109 (87.9)	
Years since diagnosis	6.24 (5.03)	4.85 (4.32)	0.02
Cancer type			
Breast	25 (21.74)	43 (34.68)	0.08
Hematologic	41 (35.65)	40 (32.26)	
Other	49 (42.61)	41 (33.06)	
Chemotherapy	92 (80.0)	97 (78.23)	0.74
Radiation	64 (55.65)	55 (44.35)	0.08
Surgery	68 (59.13)	79 (63.71)	0.47

Unadjusted and adjusted association between HBM constructs and fertility consultation after cancer

Table 3.

	No fertility consultation (<i>n</i> = 115) Mean (SD)	Fertility consultation (<i>n</i> = 124) Mean (SD)	Bivariate analyses OR (95% CI)	Multivariate analysis OR (95% CI)	Multivariate analysis, OR (95% CI)
Health Belief Model (HBM) Constructs				Model 1 ^a	Model 2 ^b
Perceived susceptibility to infertility	2.68 (1.01)	2.89 (1.05)	1.23 (0.96, 1.58)	0.97 (0.70, 1.35)	Not sig.
Perceived severity of infertility	3.10 (1.06)	3.79 (1.12)	1.77 (1.38, 2.28)	1.70 (1.25, 2.31)	2.05 (1.45, 2.89)
Perceived barriers to consultation	2.78 (0.72)	2.45 (0.70)	0.52 (0.36, 0.76)	0.40 (0.25, 0.64)	0.36 (0.22, 0.60)
Perceived effectiveness of consultation	3.52 (1.02)	4.03 (0.83)	1.86 (1.36, 2.53)	1.33 (0.92, 1.91)	Not sig.
Cues to Action,					
Cues to action, family/peers (<i>n</i> , %)	34 (29.57)	92 (74.19)	6.85 (3.88, 12.08)	4.09 (2.02, 8.27)	3.28 (1.57, 6.87)
Cues to action, doctor (<i>n</i> , %)	28 (24.56)	85 (68.55)	6.69 (3.78, 11.84)	3.91 (1.98, 7.73)	4.85 (2.31, 10.18)

^aSimultaneous regression based on the a priori theoretical framework^bControlling for income

Table 4.

Exploratory bivariate analyses of barriers as correlates of fertility consultation

	No fertility consultation (n=115) Mean (SD)	Fertility consultation (n=124) Mean (SD)
I haven't been feeling well enough to have a fertility consultation.	2.13 (0.98)	1.91 (0.90)
Having a fertility consultation would force me to make difficult decisions.	2.62 (1.17)	2.92 (1.14) *
It is too much trouble to have a fertility consultation.	2.43 (1.13)	1.79 (0.83) *
Having a fertility consultation is too expensive.	3.60 (1.11)	2.63 (1.29) *
I'm afraid that if I have a fertility consultation I might find out bad news.	3.14 (1.13)	3.02 (1.12)

* $p < 0.05$