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Fertility preservation consultation for women with cancer: are we helping patients make high-quality decisions?

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Abstract To investigate the efficacy of the current fertility preservation consultation process in patients' decision-making and socio-demographic and cognitive factors that may affect patients' decision-making, a prospective pilot survey was conducted at university-based IVF centres and included women aged 18–43 years seen for fertility preservation between April 2009 and December 2010. Patients' views on consultation and decision-making about fertility preservation were measured. Among 52 women who completed the survey, more than half (52%) requested their consultation. All patients answered that consultation was a helpful resource of information, and 73% made their decision about treatment after consultation. Decisional conflict was lower in patients who felt strongly that they were given opportunities to ask questions during the consultation ($P = 0.001$) and higher those who reported that cost was strongly influential in the treatment decision ($P < 0.001$) and who did not receive treatment ($P < 0.001$). Although consultation appeared to play a critical role in patients' decision-making about fertility preservation, the referral rate for consultation by oncologists is still poor. Decision-making appears to be significantly impaired in patients grappling with financial concerns and when the opportunity to ask questions is not felt to be sufficient. 

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KEYWORDS: consultation, decision-making, fertility preservation, cancer, embryo/oocyte banking, socio-economic status

Introduction

Increased survival after cancer treatment has heightened an awareness of long-term quality of life. Fertility preservation, a medical technique that helps cancer survivors preserve their fertility options before gonadotoxic cancer treatment such as chemotherapy and radiation, is now considered a major issue in young patients with cancer. Previous reports show that a threat to future fertility is a significant concern for cancer survivors (Bryson et al., 2000; Forman et al., 2010; Leiblum et al., 1998). Despite the heightened awareness of fertility preservation and increasing number of patients who are referred to fertility preservation specialists, only a small percentage of patients receive treatment (Kim et al., 2012; Lawrenz et al., 2011). This suggests that making decisions about fertility preservation is a complex process for many young patients with cancer.

Several factors may make the treatment decision an especially difficult one for patients. Studies have shown that people make higher quality decisions if they have three things: strong comprehension of the issues, a support system, and self-awareness about their own values about the decision (O'Connor et al., 2011). This framework applies to decision-making regarding fertility preservation; comprehension involves understanding fertility preservation, safety, time constraints and financial considerations. A patient's support system may involve a partner, her family or her healthcare providers who may have strong opinions about fertility preservation. Finally, cancer patients may have never seriously considered their own beliefs and values about reproduction. In that sense, consultation with a fertility specialist plays a key role in patients' decision-making because it is the main source of information and it supports patients' desire to learn about and seek treatment. Therefore, the consultation process must be very efficient given that often there is only a short amount of time between cancer diagnosis and the initiation of gonadotoxic cancer treatment. However, a recent report shows that, overall, patients' knowledge about fertility preservation post consultation is generally poor, which may raise concern about the efficiency of the current consultation model (Balthazar et al., 2012). Recently, several studies outside the USA assessed patients' views on their experience of fertility preservation consultation and treatment (Hill et al., 2012; Peddie et al., 2012; Yee et al., 2012). However, different countries have unique medical systems and cultural tendencies, which may allow for a range of patients' perceptions and decision-making, based on the nationality of the patient.

Decisional conflict is the state of uncertainty about the course of action to be taken. In other disciplines, the decisional conflict scale (DCS) has been used to identify modifiable risk factors in stressful medical situations (Hack et al., 2010; Metcalfe et al., 2007; Waljee et al., 2007). Patients with high DCS scores are more likely to have emotional distress, change their mind, delay decision-making, have future regret and/or blame providers (Brehaut et al., 2003; Gattellari and Ward, 2005). In the case of fertility preservation, delayed decision-making has critical importance because of the time-sensitive nature of cancer treatment. This study, which is part of the Preserving

Reproductive Opportunity After Cancer Treatment (PROACT) project, primarily aimed to evaluate the efficacy of the current fertility preservation consultation process in the USA by collecting information about patients' perceptions about the current fertility preservation consultation model at two large academic hospitals in different states. A secondary aim involved investigating which socio-demographic and cognitive factors may affect patients' decision-making using a validated tool to assess decisional conflict (O'Connor, 1995).

Materials and methods

Design

The PROACT survey is a multicentre cross-sectional study designed to evaluate patients' experience about the fertility preservation consultation process and making their decision about treatment. This is a post-consultation web-based survey which includes questions about the consultative process and the decision-making as well as an index measure of fertility preservation knowledge developed via a multistage process (Balthazar et al., 2012). The study was approved by the Institutional Review Board at the University of North Carolina at Chapel Hill (reference 09-1058, granted 10 April 2012) and at the University of Pennsylvania (reference number 812867, granted 29 November 2011) and informed consent was obtained from all participants.

Study population and recruitment

Female patients seen for fertility preservation between April 2009 and December 2010 were approached for participation 3–12 months following their consultation. Patients were included if they met the following criteria: (i) age 18–43 years; (ii) planned to receive medical treatment posing a threat to future fertility; (iii) had received a fertility preservation consultation; (iv) could read English. The upper age limit was used because the study centres do not routinely offer fertility preservation treatment to women over age 43. Women were excluded if they had received previous treatment that may have adversely affected ovarian function. The study attempted to contact all eligible subjects for enrolment. After expressing interest in the study, participants were sent a secure link to the web-based PROACT survey for completion.

The PROACT survey

Demographic and general data about the consultation process

Data regarding age, race, marital status, education level and annual income were collected for the web-based PROACT survey. Detailed information about prior or future cancer treatment was also collected, partially from the survey and also from chart extraction. Fourteen items assessed patients' perception about the consultation process, in terms of the services provided, amount of time taken from cancer diagnosis to fertility preservation consultation and

referral patterns. This study also collected data about the timing of decision-making about treatment (before or after consultation) and if participants proceeded with fertility preservation treatment.

Decision-making process about fertility preservation treatment

Decisional conflict was assessed using a modified version of a validated DCS (O'Connor, 1995). This tool included 16 items, each using a 5-point Likert response format. Final scores ranged from 0 (feels extremely supported in decision-making) to 100 (feels extremely unsupported in decision-making). Scores >37.5 indicate increased uncertainty and less satisfaction with decisions, while scores <25 indicate confidence in decisions made.

The PROACT survey included two sections designed to elucidate the specific values that played a role in the patient's fertility preservation decision. The first values-clarification exercise asked subjects to use a Likert scale to indicate how influential several factors were in their decision-making (strongly, somewhat, barely, not influential or not applicable). The second values-clarification exercise asked subjects to rank the top three factors that were most influential in their decision (1 = most influential, 3 = least influential).

Patients were also asked to rate the usefulness of various resources in making their decision, such as specific websites, handouts and consultation. Participants were asked when they made the decision about fertility preservation (before or after consultation) and with whom they discussed their options. The entire survey was piloted for feasibility, acceptability and clarity. Results were used to revise the survey before enrolling subjects.

Knowledge about fertility preservation

Patients' knowledge about fertility preservation was assessed (Balthazar et al., 2012). A set of knowledge items was developed through an iterative process, involving content validation with reproductive specialists and cognitive telephone interviews with five pilot subjects conducted by survey experts. The final fertility preservation knowledge scale was constructed using item analysis (discrimination index and item difficulty score) and item-rest correlations, in a similar fashion as other studies (Kuder–Richardson Formula 20 = 0.64) (Carpenter et al., 2009; Radosevich et al., 2004; Wright et al., 2011).

Statistical analysis

Descriptive statistics were calculated as frequency and percentage for categorical data and median and interquartile ranges (IQR) for continuous data. Wilcoxon rank sum tests were used to evaluate differences in DCS scores based on various predictor variables, such as demographics, elements of the fertility preservation process and influential factors in decision-making. A Pearson correlation coefficient measured the association between knowledge score and DCS score. A value of $P < 0.05$ was considered statistically significant. Statistical analyses were conducted using SAS version 9.2.

Results

Participant characteristics and knowledge scores after fertility preservation consultation

Among 90 eligible patients, 66 were successfully contacted by telephone, and 52 women completed the PROACT survey (79% response rate). There were no significant differences in socio-demographic data between responders and non-responders (data not shown). The median interval between the consultation and survey completion was 7 months (5–10 months).

Overall, the median age of participants was 30.7 years (24.9–36.9 years) at the time of consultation (Table 1). Most participants were white (83%), college graduates (85%), nulliparous (79%) and in a committed relationship (67%). Approximately one-half of the subjects had breast cancer (52%), with the remainder having haematological, gynaecological, brain, colon or skin cancers and 37% elected fertility preservation treatments, which included embryo, oocyte, or ovarian tissue cryopreservation. A single provider performed all of the consultations at the University of Pennsylvania. At the University of North Carolina at Chapel Hill, one provider performed the majority (83%) of consultations while the rest were performed by another provider who used a similar consultation model (similar structure and information). Only 10% of patients (five women) had reached a decision about fertility preservation before their consultation, and four of these women pursued the treatment they had decided upon. Post-consultation fertility preservation knowledge was poor, with a median knowledge score of 6 out of 13 possible points (5–9) (Balthazar et al., 2012).

Patients' perceptions about the fertility preservation consultation process

More than half (52%, 27/52) of subjects requested their referral to the fertility preservation specialist. Most patients (96%) felt that their oncologist supported their desire to pursue the consultation. Before the consultation, most patients (96%) were informed by a doctor that their cancer treatment might affect their fertility. In 71% of cases (37 women), the interval between learning they were going to receive gonadotoxic cancer treatment and the fertility preservation consultation was less than 2 weeks. The majority of patients (90%) thought that the time interval was acceptable, 81% (42/52) felt that they were offered enough time to make a treatment decision and 90% (47/52) felt that they understood their treatment options at the completion of consultation.

Less than half of the subjects (46%) did some preliminary research about fertility preservation before their consultation. The internet was the most frequently used resource (92%) by these patients. After consultation, 79% discussed their options with their oncologist, and approximately half (48%) of participants had additional contact with the fertility preservation specialist, most frequently by phone (76%) and/or another office visit (64%). A quarter (25%) of subjects noted that they had received conflicting advice from

Table 1 Characteristics of participants seen for fertility preservation.

Variable	Study population (n = 52)
Age (years)	30.7 (24.9–39.1)
DCS score (maximum = 100)	29.7 (18.0–36.9)
Knowledge score (maximum = 13)	6 (5–9)
Body mass index (kg/m ²)	25.8 (22.0–31.6)
Ethnicity	
White	43 (82.7)
Black	7 (13.5)
Hispanic	1 (1.9)
Asian	1 (1.9)
Education	
College graduate	44 (84.6)
High school graduate	8 (15.4)
Relationship status	
Single	17 (32.7)
Partnered	35 (67.3)
Income (US\$)	
≥20,000/year	44 (86.3)
<20,000/year	7 (13.7)
Previous live birth	
Yes	11 (21.2)
No	41 (78.8)
Received fertility preservation treatment	
Yes	19 (36.5)
No	33 (63.5)
Type of cancer	
Breast	27 (51.9)
Haematological	6 (11.5)
Gynaecological	12 (23.1)
Other	7 (13.5)
Distance from clinic (km)	54 (24–102)
Interval between fertility preservation consultation and survey completion (months)	7 (5–10)
Site	
University of North Carolina	40 (76.9)
University of Pennsylvania	12 (23.1)

Values are median (interquartile range) or n (%).

DCS = decisional conflict scale.

different healthcare providers about fertility preservation and cancer treatment options.

Decisional conflict scale associations

The median DCS score was 29.7 out of 100 possible points (IQR 18.0–39.1, range 4.7–64.1). Fourteen subjects had scores consistent with high decisional conflict (>37.5), 20 were in the moderate range (25–37.5) and 18 patients had low decisional conflict (<25). Univariate analysis of socio-demographic variables revealed that subjects with annual income less than \$20,000 (approximately the US poverty limit in 2011; <http://aspe.hhs.gov/poverty/11poverty.shtml>)

tended to have lower DCS scores. Age, race, relationship status, parity and level of education were not significantly associated with DCS score (Table 2).

This study then evaluated DCS scores based on subjects' perception of the fertility preservation process and influential factors in their decision-making (Table 3). While all patients agreed that they were given opportunities to ask questions during the consultation, the patients who answered 'strongly agree' had significantly lower DCS scores than those who answered 'agree' ($P = 0.001$). DCS scores were significantly lower in patients who received fertility preservation treatment compared with patients who did not ($P < 0.001$). Subjects who reported that cost was strongly influential in their treatment decision had significantly higher DCS scores compared with the patients who did not think that cost was strongly influential ($P < 0.001$). Those who thought that safety of treatment was very influential in decision-making tended to have lower DCS scores than those who did not. There was no association between DCS and knowledge scores ($P = -0.11$), discussion with anyone about treatment options or the use of additional resources before the fertility preservation consultation.

Influential factors and helpful resources in making the fertility preservation decision

In two values-clarification exercises, subjects were asked to consider the most influential factors in their decision-making about treatment. The first values-clarification exercise using a Likert scale revealed that 'desire to have a child after cancer treatment', 'amount of time needed for fertility preservation treatment' and 'cost' were the most influential factors in decision-making (73%, 43% and 41%, respectively). In the second values-clarification exercise, 40% of subjects ranked 'desire for future children' as their most influential factor, followed by 'costs' (13%), 'other' (12%) and the amount of time needed for treatment (8%). Looking at patients' top three choices, 'desire to have a child after my cancer treatment', 'cost' and 'amount of time needed for fertility preservation treatment' were the highest ranking factors in decision-making (65%, 46% and 42%, respectively; Figure 1). Among patients who received treatment, 'desire for future children' (63%), and 'partner's wishes' (11%) were the most commonly reported influential factors. Meanwhile, among those who did not receive treatment, their most influential factors included 'desire for future children' (27%), 'cost' (21%) and 'the amount of time needed for treatment' (12%).

The initial consultation with the fertility preservation specialist appeared to be the most helpful resource in making a treatment decision (Figure 2). Everyone stated that the consultation was very or somewhat helpful. Information from their cancer doctor, handouts given after fertility preservation consultation and discussion with family/friend/partner were also considered as very or somewhat helpful resources (83%, 81% and 79% respectively). Follow-up visits with the fertility preservation specialist were only used by half of patients, but 65% of patients who used them indicated that they were very helpful.

Forty-seven patients (90%) had not made up their mind about treatment before consultation. Of these 38, 47 (81%)

Table 2 Association between DCS scores and socio-demographic and clinical characteristics.

Characteristic	Study population (n, %)	DCS score (median, IQR)	
		Variable present	Variable Absent
Age >30 years	28 (53.8)	31.3 (23.4–39.1)	25.0 (13.3–37.5)
Caucasian	43 (82.7)	29.7 (18.8–39.1)	26.6 (14.1–37.5)
College education	44 (84.6)	29.7 (18.8–39.1)	23.4 (11.7–40.6)
Income ≥US\$20,000	44 (86.6)	31.3 (18.0–39.1)	21.9 (9.4–21.9)
Parity ≥1	11 (21.2)	29.7 (21.9–39.1)	29.7 (17.2–39.1)
In a relationship	35 (67.3)	29.7 (15.6–39.1)	29.7 (18.8–37.5)
Breast cancer	27 (51.9)	29.7 (18.8–37.5)	29.7 (15.6–43.8)

Maximum decisional conflict scale (DCS) score = 100.

Wilcoxon rank sum test showed no statistically significant differences.

Table 3 Association between DCS scores and subjects' perception of the fertility preservation consultation process and influential factors in decision-making.

Characteristic	Study population (n, %)	DCS score (median, IQR)		P-value
		Variable present	Variable Absent	
Fertility preservation process				
Researched before consultation	24 (46.2)	32.8 (25.8–39.1)	21.9 (13.3–39.1)	NS
Oncologist supported interest in fertility preservation	50 (96.2)	29.7 (18.9–39.1)	12.5 (12.5–12.5)	NS
Given opportunities to ask questions during consultation ^a	40 (76.9)	26.6 (15.6–36.7)	41.4 (35.2–52.3)	0.0012
Brought someone to the consultation	37 (71.2)	32.8 (21.9–42.2)	26.6 (14.1–34.4)	NS
Had fertility preservation treatment	19 (36.5)	18.8 (12.5–29.7)	37.5 (25.0–43.8)	0.0006
After visit, felt had understood options	47 (90.4)	29.7 (18.8–39.1)	26.7 (14.1–39.1)	NS
Before visit, had decided about treatment	5 (9.6)	29.7 (12.5–37.5)	26.7 (18.8–39.1)	NS
Influential factor in decision-making ^b				
Desire to have a child after cancer treatment ^{b,c}	37 (72.5)	26.6 (15.6–39.1)	36.7 (26.6–37.5)	NS
Amount of time needed for fertility preservation ^{b,c}	22 (43.1)	37.5 (18.8–42.2)	28.1 (17.2–35.9)	NS
Safety of fertility preservation ^{b,c}	16 (31.4)	25.0 (12.5–37.5)	32.8 (21.9–40.6)	NS
Cost ^c	21 (42.0)	37.5 (29.7–43.8)	21.9 (14.1–34.4)	0.0008

Maximum decisional conflict scale (DCS) score = 100. Wilcoxon rank sum test.

NS = Not significant

^aAnalysis of women who answered strongly agree versus agree. ^bCompleted by 51 subjects.

^cCompleted by 50 subjects; analysis of women who answered very influential versus somewhat, barely or not influential.

made their decision soon after consultation. The remaining nine needed additional contact with the fertility specialist to make their final decision.

Discussion

This novel study reports the efficacy of the current fertility preservation consultation process and the predictors of high decisional conflict after consultation at two large academic hospitals in different states in the USA. Patients appeared to be overall satisfied with the consultation process and the majority of women agreed that they had enough time to make a decision about treatment. A large percentage (65%) of women had a moderate or severe amount of decisional conflict when considering their treatment options.

Decision-making appears to be significantly more difficult in patients grappling with financial concerns and when the opportunity to ask questions was not felt to be sufficient. In making their decision, patients tended to consider how much they desire children in the future, costs of treatment and the amount of time needed for treatment. Of note, patients who received fertility preservation treatment had lower DCS scores compared with the patients who did not.

These findings from the PROACT study demonstrate that patients appear to be satisfied overall with the current fertility preservation consultation process, in terms of timeliness and information provided. Most patients report making their decision about treatment after their consultation with a fertility specialist. Interestingly, it is noted that more than half of the referrals to a fertility specialist were

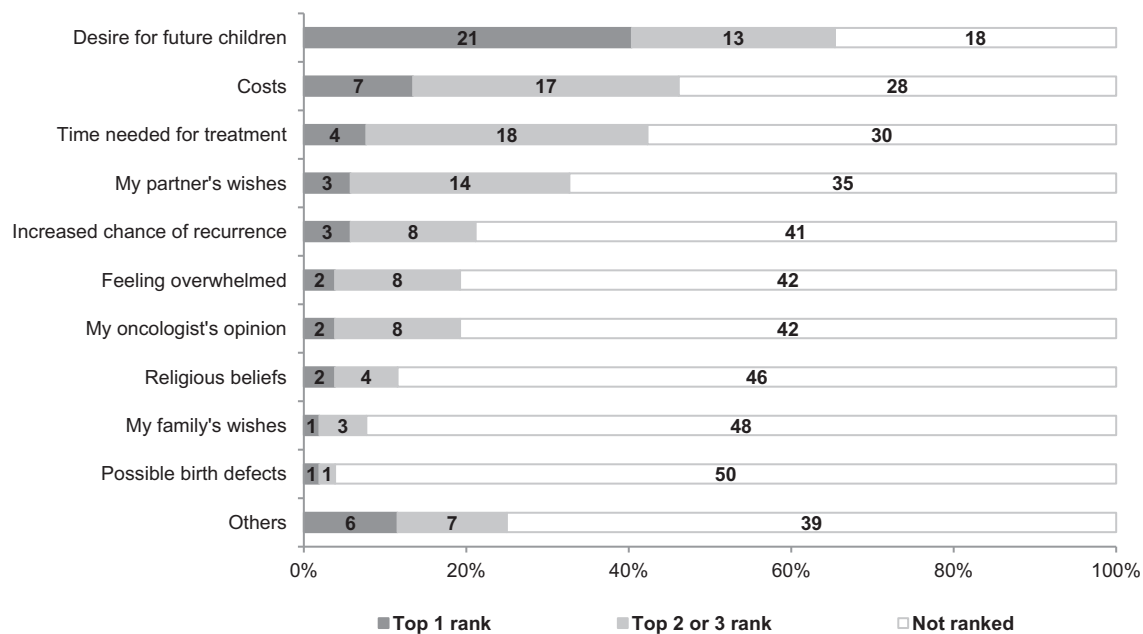


Figure 1 Influential factors in decision-making about fertility preservation treatment. Numbers in bars indicate the number of patients.

initiated by patients, not by oncologists. This finding is consistent with a recent study reporting that fertility issues are not addressed routinely by physicians during patients' cancer care (Yee et al., 2012). Although the American Society of Clinical Oncology recommends oncology professionals should discuss fertility preservation issues and refer patients to a fertility specialist (Lee et al., 2006), the referral rates to fertility specialists still remain low (Goodman et al., 2012). The current study reinforces the need for early referral to a fertility specialist as most patients found this consultation to be useful in their decision-making process.

Several factors contribute to making the fertility preservation decision an especially challenging one. The cost involved in treatment was mentioned repetitively as an important factor in the decision, likely because treatment is often not covered by insurance in the USA (Quinn et al., 2011). Participants who stated that cost was highly influential in their decision had significantly higher levels of decisional conflict compared with those who did not feel this way. On the other hand, subjects whose annual income was below the poverty line had less decisional conflict, likely because treatment was so unattainable for them that there was no decision to seriously consider. Before a consultation, the majority of patients are unaware of the costs associated with treatment or believe that it is expensive (Balthazar et al., 2011). Perhaps altering the consultation process to routinely provide detailed and individualized information about the cost of treatment, and also financial aid resources, may decrease patients' decisional conflict. Several recent studies reported the effect of fertility preservation cost on patients' decision-making (Hill et al., 2012; Yee et al., 2012). However the results are conflicting, which likely reflects differences in healthcare system fee structures between different countries. In the USA, patients with cancer may consider fertility preservation treatment to be an additional financial burden, which may have a profound influence on patients' decision-making.

This study found that the fertility preservation consultation process was associated with decision, both beneficially and detrimentally. The discussion about fertility preservation often involves medical technology that is unfamiliar to most patients: their lack of comprehension about treatment and safety may affect their decision-making (Peate et al., 2011). The present study found that decisional conflict was lower when patients felt strongly that they had the opportunity to ask questions at the consultation. In general, patients who participate more actively in their consultation report greater satisfaction with their care and have improved psychosocial outcomes compared with those who play a more passive role (Street et al., 1995). In a survey study about fertility preservation, the majority of participants preferred as much information as possible and many report actively seeking out information (Peate et al., 2011). That being said, previous studies have demonstrated that patients' fertility preservation knowledge prior to consultation is generally poor (Balthazar et al., 2011; Peate et al., 2011). In the present study, 100% of patients answered that the consultation was a helpful resource of information and 73% of patients made up their mind about treatment after the consultation. Recently, Peate et al. (2011) performed a survey study prior to consultation and suggested that a low level of pre-visit knowledge about fertility preservation was associated with increased pre-visit decisional conflict. Interestingly, in the present study, there was no association between post-visit knowledge score and post-visit DCS score. This may be because overall patients' knowledge was improved after the consultation so it no longer had an association with high/low decisional conflict. Also, this study's rate of high decisional conflict (27%) which was obtained after consultation was lower than the pre-visit rates of high decisional conflict (63.1%) found in the study by Peate et al. (2011). Information about fertility preservation options obtained during the consultation may promote decreased decisional conflict.

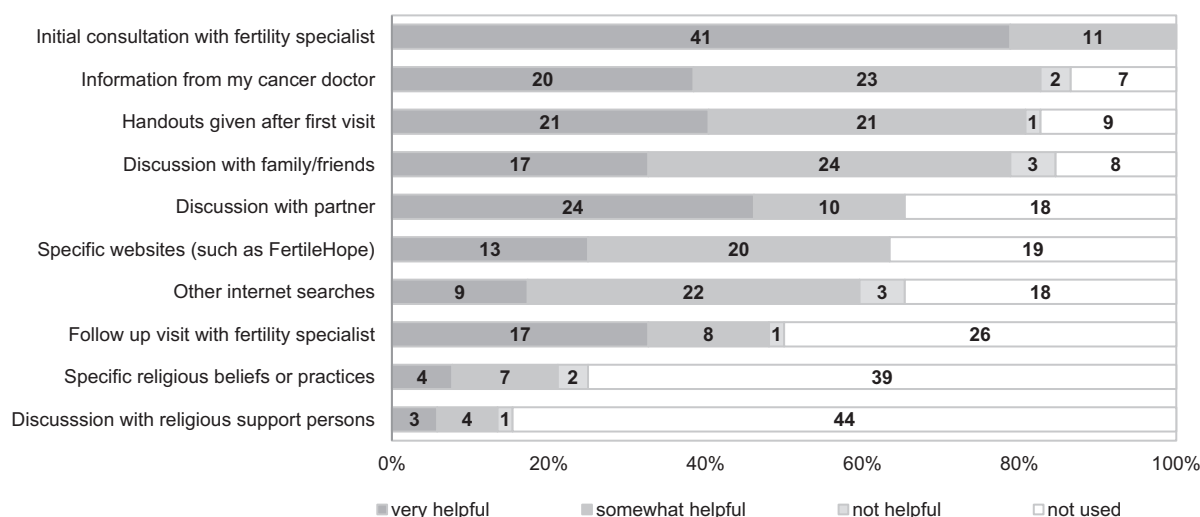


Figure 2 Helpful resources in making patients' fertility preservation treatment decisions. Numbers in bars indicate the number of patients.

Patients who did not pursue treatment were found to have higher levels of decisional conflict. High levels of decisional conflict have been associated with delayed decision-making (Brehaut et al., 2003). Cancer patients with heightened stress about the fertility preservation decision might lose the opportunity to pursue fertility preservation because of the limited amount of time for treatment. Interestingly, it appeared that patients who did not undergo treatment felt that the amount of time needed was more important than the patients who received treatment. It was recently reported that the rate of undergoing fertility preservation treatment was significantly lower in breast cancer patients who received neoadjuvant chemotherapy compared with women who underwent surgery first, likely because neoadjuvant chemotherapy restricts the time available for fertility preservation (Kim et al., 2012). Perhaps the association between higher levels of decisional conflict and not pursuing fertility preservation is partially explained by the extra decisions that some patients face related to time constraints and treatment options (such as adjuvant versus neoadjuvant chemotherapy).

This cross-sectional study has several limitations. First, there was a relatively small number of patients, which may have affected the ability to determine subtle differences in variables that contribute to DCS score. Second, the survey was conducted at a single time point, well after the decision was made, which might have introduced recall bias.

This is one of the few studies to have looked at the predictors of high decisional conflict after fertility preservation consultation and to have assessed the factors influencing patients' decision-making. This study also evaluated the efficiency of the current fertility preservation consultation process and provides important new information that will improve counseling and help patients make better decisions. Future research will be required to develop useful decision aid tools that can help improve the quality of cancer patients' decision-making about fertility preservation.

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