

# It's Now or Never: Fertility-Related Knowledge, Decision-Making Preferences, and Treatment Intentions in Young Women With Breast Cancer—An Australian Fertility Decision Aid Collaborative Group Study

Michelle Peate, Bettina Meiser, Michael Friedlander, Helen Zorbas, Susan Rovelli, Ursula Sansom-Daly, Jennifer Sangster, Dusan Hadzi-Pavlovic, and Martha Hickey

From the Prince of Wales Clinical School, University of New South Wales; Prince of Wales Hospital; Royal Hospital for Women; Black Dog Institute, Randwick; National Breast and Ovarian Cancer Centre, Surry Hills, New South Wales; and the Royal Women's Hospital, the University of Melbourne, Parkville, Victoria, Australia.

Submitted August 9, 2010; accepted January 25, 2011; published online ahead of print at www.jco.org on March 28, 2011.

Supported by the Cancer Council, New South Wales, Australia (Grant No. RG06-13). B.M. is supported by a Career Development Award from the National Health and Medical Research Council of Australia (Grant No. 350989).

Presented in part at the International Psycho-Oncology Society (IPOS) 9th World Congress for Psycho-Oncology, London, United Kingdom, September 17-19, 2007; Fertility Society of Australia conference, Brisbane, Australia, October 20-22, 2008; Clinical Oncological Society of Australia (COSA) conference, Adelaide, Australia, November 14-16, 2007; COSA conference, Adelaide, Australia, November 18-20, 2008; 12th World Congress for Psycho-Oncology (IPOS), Quebec City, Canada, May 27-29, 2010; 12th National Breast Care Nurse Conference, Coogee, Australia, March 18-19, 2010.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

Corresponding author: Michelle Peate, PhD, Psychosocial Research Group, Department of Medical Oncology, Level 3 Dickinson Building, Prince of Wales Hospital, Randwick, NSW, Australia 2031; e-mail: m.peate@unswalumni.com.

© 2011 by American Society of Clinical Oncology

0732-183X/11/2913-1670/\$20.00

DOI: 10.1200/JCO.2010.31.2462

## ABSTRACT

### Purpose

For many young women with early breast cancer, fertility is a priority. Interventions to retain fertility options generally need to be accessed before chemotherapy, but many women do not receive information regarding these options in a timely fashion. Knowledge about fertility and decisional conflict has not previously been measured in young patients with breast cancer considering future pregnancies.

### Methods

One hundred eleven young women with early breast cancer who had not yet completed their families were recruited around the time of diagnosis. Knowledge regarding fertility-related information, decisional conflict, and preferences regarding fertility information and decision making was measured.

### Results

From a potential fertility-related knowledge score of 10, the mean was 5.2 (standard deviation = 2.3; range, 0 to 10). Decreased knowledge was associated with increased decisional conflict about pursuing fertility preserving interventions (odds ratio [OR] = 0.57; 95% CI, 0.44 to 0.73;  $P < .001$ ). Thirty-one percent of women reported that they would consider undertaking in vitro fertilization (IVF) as a method to conserve their fertility, whereas 38% were uncertain. Consideration of IVF was not related to whether subjects were in a committed relationship (OR = 1.20;  $P = .716$ ) or a definite desire for more children (OR = 1.54;  $P = .513$ ).

### Conclusion

Around diagnosis, many young patients with breast cancer have low levels of knowledge about fertility issues. Further, low knowledge is associated with increased decisional conflict, which is likely to undermine the quality of decision making. These findings suggest that targeted and timely fertility information may reduce decisional conflict and increase informed choice. Neither relationship status nor firm plans regarding future children reliably predict desire to pursue fertility preservation.

*J Clin Oncol* 29:1670-1677. © 2011 by American Society of Clinical Oncology

## INTRODUCTION

Approximately 6% to 7% of women diagnosed with breast cancer are younger than 40 years at the time of their diagnosis.<sup>1</sup> Patients recently diagnosed with cancer may be under pressure to make rapid decisions regarding fertility interventions. To make informed decisions, women need to understand the effects of cancer treatment on fertility and the available options.<sup>2</sup> Previous studies have indicated that younger women have unmet fertility-related information needs and that fertility information is a priority.<sup>3-7</sup> Previous reports indicate that fertility

preservation is often not discussed with patients, with 34% to 72% of women reporting retrospectively that fertility issues were discussed and only 51% reporting that concerns were addressed adequately.<sup>3,5,8,9</sup> Since the publication of these reports, the American Society for Clinical Oncology recommends that fertility preservation be discussed early in the treatment trajectory.<sup>10</sup> There have been no recent data published to reflect current clinical management.

The aim of this study was to explore three key areas relevant to fertility in younger patients with breast cancer: (1) level of knowledge about fertility

and fertility treatment options; (2) predictors of knowledge, decisional conflict (decisional uncertainty), and treatment intentions; and (3) fertility-related information and decision-making preferences. This information will assist in understanding how best to manage fertility in younger patients with breast cancer.

## METHODS

### Recruitment Procedure

Data were collected as part of a national prospective trial to assess the efficacy of a fertility-related decision aid for young women with early breast cancer (Peate et al, manuscript in preparation). Participants were patients with early breast cancer (stage I, IIA, and IIB, excluding women with ductal carcinoma in situ) referred to one of 19 oncology clinics around Australia from 2006 to 2009. The study was approved by the institutional review boards at all sites. Inclusion criteria included age 18 to 40 years, diagnosed with early breast cancer, and reported incomplete families. Subjects were all proficient in English, premenopausal at diagnosis, able to give informed written consent, and had not commenced adjuvant therapy. Consecutive eligible women were identified by breast care nurses at each site and approached to participate within a week of their diagnosis before their oncologist and fertility specialist appointments. Patients were requested to complete the baseline survey as soon

as they received it, and consequently, the majority of women were not aware of the kind of treatment they would receive.

### Sample Size

A total of 141 eligible women were invited to participate. Eleven women declined to participate at invitation. An additional 19 women failed to return the questionnaire, yielding a final sample size of 111. This represented 79% of eligible subjects and 85% of those agreeing to participate.

### Predictor Variables

**Demographic, reproductive, and disease-related data.** Data included age at diagnosis, marital status, parity, desire for more children, highest level of education completed, and ethnicity.

**Perceived importance of receiving fertility information.** Two items assessed the perceived importance of receiving information on the impact of cancer treatment on fertility and the available fertility options.

**Information preference style.** On the basis of a measure adapted from Cassileth,<sup>11,12</sup> three items asked participants to rate the amount of desired information about fertility issues, how active they had been in obtaining such information, and the type of information wanted.

**Medical decision-making preference style.** This item assessed participants' preferences for participation in making decisions about treatment.<sup>13</sup>

**Hospital Anxiety and Depression Scale.** The 14-item Hospital Anxiety and Depression Scale is a widely used measure of emotional disturbance and has two subscales measuring anxiety and depression.<sup>14</sup> Scores  $\leq 7$  indicate a noncase, scores between 8 and 10 identify doubtful cases, and scores  $\geq 11$  indicate definite cases of anxiety or depression.<sup>15</sup> Provisions for addressing clinically significant cases of anxiety and depression were established with each recruitment site before commencement of the study.

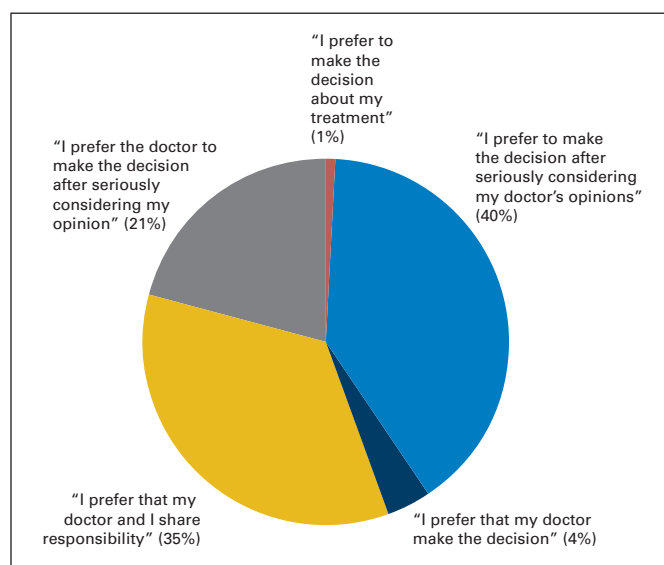
**Attitude toward fertility treatment.** Adapted from the attitudes subscale of the Multidimensional Measure of Informed Choice,<sup>16</sup> it includes five items assessing attitudes toward fertility treatment. Summing individual items scores produced a total score (range, 5 to 35), with higher scores indicating more negative attitudes.

### Outcome variables

**Knowledge of fertility-related information.** Ten true-false items developed for this study measured knowledge of assisted reproductive technologies, the impact of different therapy regimens on fertility, and the impact of pregnancy after breast cancer on prognosis. A total knowledge score was calculated (range, 0 to 10). The scale was found to have satisfactory internal consistency with coefficient  $\alpha$  of 0.63.

Characteristic	No. of Patients	%
Age, years		
Mean	33	
Range	21-40	
Length of relationship, years		
Mean	4	
Range	0.25-18	
Knowledge score (of 10)		
Mean	5.2	
Range	0-10	
Marital status		
Single, divorced, or separated	27	24.3
Committed relationship, de facto, married, or engaged	84	75.7
Parity		
Biologic children	34	31
No children	77	69
Plan for children in the future		
Yes	78	70
Uncertain	33	30
Language spoken at home*		
English	85	77.3
Other	25	22.7
Highest level of education		
High school	18	16.2
TAFE certificate/diploma	25	22.5
University degree (undergraduate and postgraduate)	68	61.2
Employment status		
Full-time, self-employed	72	64.9
Part-time, casual	18	16.2
Unemployed, home duties, student	15	13.5
Other	6	5.4

Abbreviation: TAFE, technical and further education.  
\*One participant did not indicate language spoken at home.



**Fig 1.** Patient preferred roles in medical decision making, as measured by the question related to the medical decision-making style preferred.

**Decisional Conflict Scale (DCS).** The low literacy version of this scale comprises 10 items to assess decisional conflict regarding different fertility treatments. Scores more than 37.5 on the scale indicate high decisional conflict, which is characterized by decision delay and/or uncertainty about decision implementation.<sup>17</sup>

**Intended decision about fertility treatment.** Two items asked participants “At this point in time, are you leaning towards...waiting to see if fertility returned after treatment” and/or “in vitro fertilization.” Additionally, participants were asked whether there were any fertility treatments, other than in vitro fertilization (IVF), they had considered and their intentions regarding these.

### Statistical Analyses

To test associations between predictor and outcome variables, nonparametric tests were used for non-normally distributed outcome variables and their parametric equivalents for normally distributed outcome variables. Predictor variables with  $P < .10$  in bivariate analyses were included in multivariate analyses.<sup>18</sup> A progressive, backward elimination modeling strategy was used until a final model was obtained containing only variables with  $P < .05$ . Due to their importance, age, marital status, education level, and tumor grade were assessed for inclusion in all regression models as potential confounders. Each potential confounder was entered into the model one at a time. If it resulted in a more than 10% change in the coefficient of any predictor, the variable was considered a confounder and was retained in the final model.<sup>18</sup> Our sample size provided 80% power at a significance level of  $P < .05$  to detect a correlation of  $r = 0.25$  between knowledge scores and decisional conflict. This corresponds to a medium effect size correlation.<sup>19</sup> Ordinal logistic regression was conducted to examine predictors of intention to undergo IVF. In this analysis, two meaningful divisions of fertility treatment intentions were examined: (1)

“leaning toward” a treatment versus “not sure” and “not leaning toward”; and (2) “leaning toward” and “not sure” versus “not leaning toward,” so that all observations are included in the analysis at all stages.<sup>20</sup>

## RESULTS

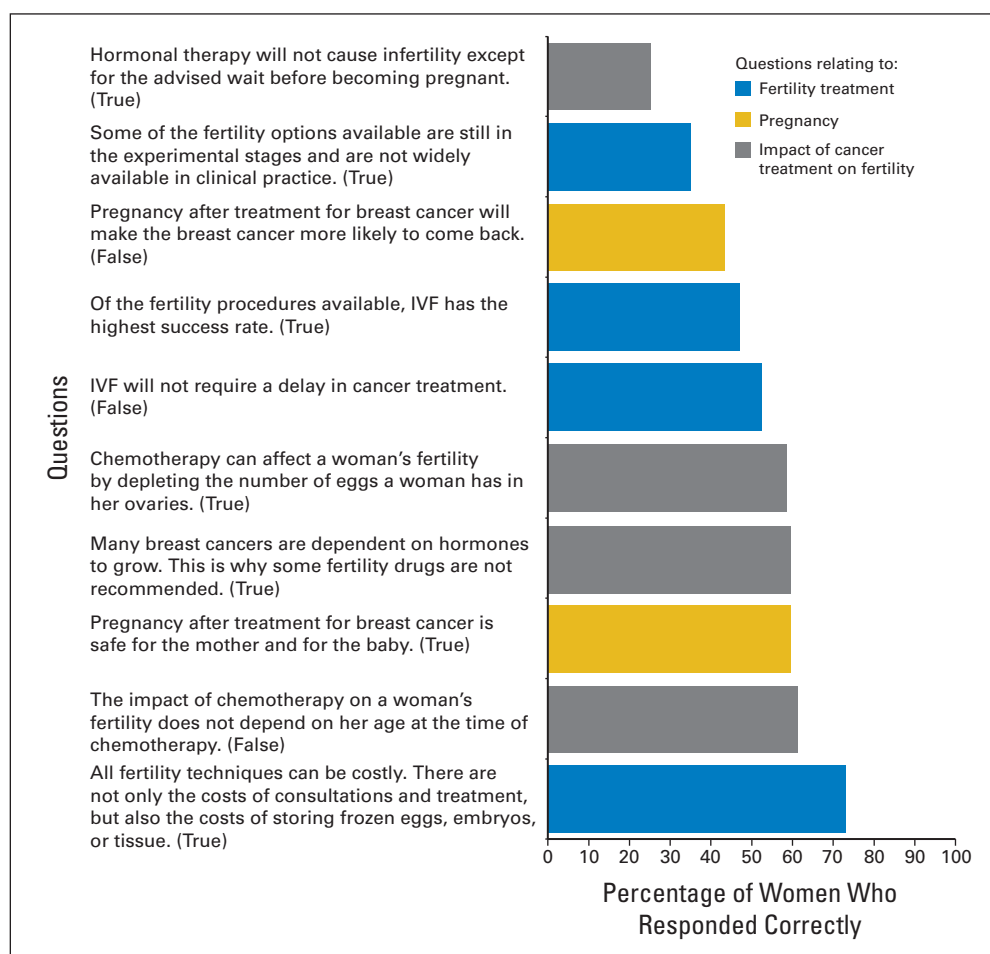
### Response Rate and Participant Characteristics

The mean age of participants was 33 years, ranging from 21 to 40 years. Almost 76% of women were in a committed relationship, and the average length of relationships was four years (standard deviation [SD] = 3.5; range, 0.25 to 18 years). Further demographic characteristics are presented in Table 1.

The majority of subjects did not have biologic children (69%,  $n = 76$ ). Of this group, 82% ( $n = 62$ ) reported that they planned to have children or that they were undecided whether they wished to have children (18%,  $n = 14$ ). Of the 35 women who already had children, 46% ( $n = 16$ ) definitely planned to have more children, and the rest (54%,  $n = 19$ ) were unsure. Overall, most participants reported that they planned to have (more) children (70%,  $n = 78$ ).

### Information Preference Style

All participants reported that receiving information on the impact of cancer treatment on fertility was important, with 65% and 22% stating that it was extremely or very important, respectively. Similarly,



**Fig 2.** Percentages of women responding correctly to fertility-related information knowledge items (ordered from lowest correct answers to highest). IVF, in vitro fertilization.

all women reported receiving information on potential fertility preserving interventions as important, with 63% describing it as extremely important and 20% as very important. No women reported this information as unimportant.

The majority of participants (74%) indicated a preference for as much information as possible about the effects of cancer treatment on future fertility, and all participants reported wanting information to some extent. Similarly, most participants (73%) reported that they wished to know both good and bad news about fertility. Twelve percent (12%) reported that they preferred a minimal amount of information, and 15% preferred only good news.

Twenty-three percent (23%) reported being quite active and 15% reported being very active in seeking out information about the effects of cancer treatment on future fertility, whereas the remainder reported they had been moderately (23%), little (26%), or not at all active (14%). Participants with higher education levels were more likely to desire and actively seek information than those with a lower education level ( $r = 0.21$ ,  $P = .03$ ). In post hoc analysis, those who had actively sought information had higher knowledge scores ( $r = 0.49$ ,  $P < .001$ ).

### Medical Decision-Making Preference Style

Only 1% of participants preferred to make the decision about their medical treatment without consultation with their doctor, 40% preferred to make the final decision after seriously considering their doctor's opinion, 35% reported that they preferred to share the responsibility for decision making with their doctor, 21% preferred that their doctor make the final decision while seriously considering their opinion, and 4% preferred to leave all decisions to their doctor (Fig 1).

### Attitudes to Fertility Treatments

Overall, participants rated fertility treatments as positive (mean attitude score = 14.0; SD = 6.6; range, 5 to 35).

### Hospital Anxiety and Depression Scale

The mean anxiety score was 8.7 (SD = 4.4; range, 1 to 21), and the mean depression score was 4.9 (SD = 4.2; range, 0 to 21). Thirty-two percent and 10% of women showed evidence of levels of anxiety and depression, respectively, that warranted a need for clinical intervention. In post hoc analyses, anxiety ( $r = 0.11$ ;  $P = .28$ ) and depression ( $r = 0.12$ ;  $P = .27$ ) scores were not correlated with perceived importance of information.

### Knowledge of Fertility-Related Information

The mean total knowledge score was 5.2 (SD = 2.3; range, 0 to 10). Overall, the percentages of women who responded correctly to particular items ranged from 25% to 73%. Forty-five percent of participants scored correctly on six or more items. Figure 2 shows the percentages of participants who correctly responded to the fertility-related knowledge items. Table 2 shows the results from bivariate analyses of subjects' knowledge of fertility-related information. When entered into a linear regression model, only Information Preference Scale scores ( $t = 2.66$ ,  $P = .013$ ) were positively associated with level of knowledge.

### Decisional Conflict Scale (DCS)

The mean DCS score regarding fertility interventions was 48.3 (SD = 31.9; range, 0 to 100), with 63.1% of participants being categorized as having high decisional conflict. The mean subscale scores were

**Table 2.** Bivariate Associations With Knowledge of Fertility-Related Information

Variable	No.	Mean	SD	<i>r</i>	<i>t</i>	<i>P</i>
Age, years	111			0.08		.40
Educational level	111			0.14		.14
Relationship length	38			0.40		.013*
Information preference style score	111			0.39		< .001*
Importance of information on impact of cancer treatment on fertility	95			-0.003		.98
Importance of information on impact of fertility treatment	95			0.007		.95
Medical decision-making preference style	111			0.25		.007*
Anxiety	111			-0.15		.13
Depression	111			-0.09		.35
Attitude toward fertility treatments score	108			-0.10		.30
Desire for more children					1.06	.29
Yes	78	4.79	2.41			
Unsure	33	5.29	2.27			
Committed relationship					-1.92	.057*
No	27	4.41	2.29			
Yes	84	5.38	2.29			
Parity					1.15	.25
No	76	5.32	2.35			
Yes	35	4.77	2.22			
Difficulty in becoming pregnant					-0.23	.82
No	42	5.19	2.37			
Yes	17	5.35	2.71			
Previous fertility treatment					-0.43	.67
No	25	5.12	1.99			
Yes	8	5.50	2.67			

\*Variables entered into regression model.

**Table 3.** Bivariate Associations With the Decisional Conflict Scale

Variable	No.	Mean Rank	<i>r</i>	<i>Z</i>	<i>P</i>
Age, years	111		−0.086		.37
Educational level	111		0.007		.94
Relationship length	38		0.17		.30
Information preference style score	111		−0.23		.016*
Importance of information on impact of cancer treatment on fertility	95		0.046		.66
Importance of information on impact of fertility treatment	95		0.019		.85
Medical decision-making preference style	111		0.011		.91
Anxiety	111		0.082		.39
Depression	111		0.14		.14
Knowledge score	111		−0.45		< .001*
Attitude toward fertility treatments score	108		0.08		.41
Desire for more children				−0.18	.86
Yes	78	56.35			
Unsure	33	55.17			
Committed relationship				−0.38	.97
No	27	56.20			
Yes	84	55.93			
Parity				−1.58	.12
No	76	52.74			
Yes	35	63.09			
Difficulty in becoming pregnant				−0.89	.37
No	42	31.26			
Yes	17	26.88			
Previous fertility treatment				0.60	.61
No	25	17.50			
Yes	8	15.44			

\*Variables entered into regression model.

57.0 for “uncertainty” (SD = 38.8), 50.6 for “informed” (SD = 41.3), 55.2 for “values clarity” (SD = 40.3), and 35.6 for “support” (SD = 29.9). Table 3 shows results from bivariate analyses of overall DCS scores using Spearman’s correlations. In the final logistic regression model, knowledge scores remained significantly associated with DCS scores (odds ratio [OR] = 0.57; 95% CI, 0.44 to 0.73;  $P < .001$ ) after adjusting for confounding variables; that is, subjects with higher knowledge scores reported significantly lower levels of decisional conflict.

### Intended Decisions About Cancer and Fertility Treatments

Approximately a third (36%) of participants were leaning against using fertility treatments (ie, preferring to “wait and see”), and a similar proportion (31%) were considering IVF. Bivariate analyses of treatment intentions are shown in Table 4. The final ordinal regression model showed that women who rated fertility information as important were more likely to consider IVF (OR = 2.14;  $P = .004$ ), and women who had negative attitudes toward fertility treatment were less likely to consider IVF (OR = 0.84;  $P < .001$ ). IVF treatment intentions were not associated with being in a committed relationship (OR = 1.20;  $P = .716$ ) or a definite desire for more children (OR = 1.54;  $P = .513$ ) using regression analysis.

## DISCUSSION

This is the first study to prospectively measure fertility-related knowledge and intentions and information preferences about fertility in a

large group of young women with breast cancer who had not yet completed their families. There are five principal novel findings from this study, which are described next.

First, many young patients with breast cancer were unaware of key facts regarding the impact of breast cancer treatments on fertility and potential fertility preserving options, as well as pregnancy after breast cancer. Because no standardized measures of fertility- and cancer-related knowledge were available, a purposively developed scale was used, on the basis of the findings of Thewes et al.<sup>5</sup> It should be recognized that this scale may not be the best measure of fertility-related knowledge and that the “correct” answers to some questions are controversial, with conflicting data and opinions among experts. Future research should look into the development of a standardized scale to provide a more accurate measure for knowledge and allow for better comparison across populations. However, as fertility-related knowledge in young women with early breast cancer has not previously been reported, our data provide novel information about levels of fertility knowledge in this population. On average, our sample only scored correctly on half the items assessing knowledge, with only 45% scoring above six on the scale. Very little is known about fertility-related knowledge in younger women with breast cancer. Only one recent study has retrospectively reported women’s “self-assessed” knowledge at approximately 6 months after diagnosis when chemotherapy is likely to have been completed.<sup>21</sup> Most women identified themselves as having limited knowledge (“a little” or “some”) regarding infertility related to cancer treatment and fertility preservation. These prospective data support published retrospective findings that young patients with breast cancer have inadequate knowledge about

**Table 4.** Bivariate Associations With Intentions for In Vitro Fertilization

Variable	No.	Mean Rank	<i>r</i>	<i>Z</i>	<i>P</i>
Age in years	109		−0.10		.28
Educational level	109		0.034		.73
Relationship length	37		−0.12		.49
Information preference style score	109		0.31		.001*
Importance of information on impact of cancer treatment on fertility	93		0.32		.002*
Importance of information on impact of fertility treatment	93		0.38		< .001*
Medical decision-making preference style	109		−0.01		.92
Anxiety	109		0.018		.85
Depression	109		−0.079		.41
Attitude towards fertility treatments score	106		−0.50		< .001*
Desire for more children				−4.47	< .001*
Yes	76	63.39			
Unsure	33	35.68			
Committed relationship				< 0.001	1.00
No	27	55.00			
Yes	82	55.00			
Parity				−3.13	.002*
No	75	61.00			
Yes	34	41.76			
Difficulty in becoming pregnant				−0.76	.45
No	41	28.02			
Yes	16	31.50			
Previous fertility treatment				0.74	.76
No	25	16.78			
Yes	7	15.50			

\*Variables entered into regression model.

fertility issues. This study is the first to report levels of fertility-related knowledge at diagnosis. This has clear implications for the level and nature of fertility information required by young patients with breast cancer at diagnosis. This also has implications for treatment-related counseling.

Second, women with higher levels of fertility-related knowledge had lower levels of fertility-related decisional conflict. Decisional conflict is a validated measure of the efficacy of decision aids.<sup>22</sup> More than 60% of participants were categorized as having high decisional conflict related to fertility options, similar to levels reported for surgical decision making (57%).<sup>23</sup> There is some controversy in measuring decision quality; however, it is improved when decisional conflict is low, implying decision follow through.<sup>17,24–26</sup> Delay in decision making may have considerable implications because once chemotherapy has commenced, fertility preservation options are likely to be reduced.<sup>10</sup> The association between knowledge and decisional conflict suggests that improvements in patient knowledge may reduce uncertainty about fertility treatment decisions, which in turn may increase decision quality and informed choice. Informed choice improves psychological adjustment to breast cancer in the longer term.<sup>27</sup>

Third, fertility related information was considered very important by young patients with breast cancer, and all subjects wanted information on fertility treatments and fertility-preserving interventions. Because this information was equally important to women, irrespective of anxiety and/or depression levels, clinicians should not avoid providing this information because of concomitant mental health concerns. Additionally, approximately 70% of recruits were childless at diagnosis. With increasing age at first birth, it is likely that increasing numbers of women are childless at breast cancer diagnosis,

thus highlighting the importance of fertility discussions. Furthermore, these results indicate that women are ill-equipped to make informed fertility decisions and that the onus of the discussion, and referral, lies with the clinician.

State anxiety levels were high in our population, but levels of depression reflect general population prevalence.<sup>28</sup> Anxiety can negatively influence information retention during medical consultations,<sup>29</sup> which can be improved by the provision of written information.<sup>30</sup> Our findings support the provision of timely written information about fertility options to support discussions with young patients with breast cancer. This is particularly important considering the pressure for rapid decision making and potential delay of cancer treatments. Lack of information can increase anxiety and negatively influence decision making.<sup>31</sup> Anxiety levels were not correlated with fertility knowledge level or desire for information. This suggests that even though patients with breast cancer may be anxious, this does not obviate their wish for information about fertility, and clear information should be provided to all women.

Overall, our data support results from previous retrospective studies that indicate unmet information needs about fertility.<sup>3,5</sup> National and international guidelines recommend that health professionals provide young patients with breast cancer with fertility information at the earliest possible opportunity.<sup>10,32</sup>

Our fourth novel finding is that most young women wanted as much information as possible about fertility around the time of diagnosis, including good and bad news. This is the first report of the extent and nature of fertility information wanted by young patients with breast cancer. Those who had actively sought information had higher knowledge levels, and knowledge levels were

not associated with educational level. Because new techniques are rapidly emerging,<sup>33</sup> information needs to be regularly updated to ensure that women are making informed decisions about fertility interventions.

Finally, most participants preferred an active decision-making role regarding fertility options. It is known that younger patients with breast cancer prefer an active role in decision making but also wish to consider medical advice.<sup>13,34</sup> Our results confirm findings that patients diagnosed with lung or colorectal cancers prefer active decision making when evidence is uncertain.<sup>35</sup> Approximately one third of participants preferred a collaborative decision-making role. Interestingly, the great majority of those who preferred a passive role (one quarter of participants) still wished for their opinions and personal values to be considered before the doctor makes the decision. Informed opinion requires information. Responsibility for decision making may also create anxiety and remorse if the outcome is not what women expected. Our findings support the role of a decision-making tool, such as a decision aid, even if the final decision remains with the health care professional.

Approximately one third of participants would consider IVF for fertility preservation. This rate is higher than that reported elsewhere<sup>36</sup> and may reflect differences in insurance coverage across countries,<sup>37</sup> which may have influence decision-making. IVF treatment intentions were not associated with being in a committed relationship, despite the difficulties that can arise when women do not have easy access to donor sperm. Further, consideration of IVF was not associated with having a definite desire for more children. Decision making regarding IVF is complex for any couple and may be further complicated by relationship issues and time pressures. Our findings suggest that single women and those who remain undecided regarding future children may also wish to discuss IVF and other fertility preservation options before chemotherapy for breast cancer.

In conclusion, this study demonstrates that young patients with breast cancer have significant gaps in fertility-related knowledge at the time of diagnosis and that fertility information is a priority. Further, we have shown that most wish to be actively involved in decision making and that many would consider invasive procedures such as IVF to preserve fertility.

Future research should include the use of prospective designs to investigate fertility-related knowledge and decision-related outcomes over time and elucidate the mechanisms involved in the complex decision-making processes regarding fertility options for this population.

## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

## AUTHOR CONTRIBUTIONS

**Conception and design:** Michelle Peate, Bettina Meiser, Michael Friedlander, Helen Zorbas, Susan Rovelli, Ursula Sansom-Daly, Martha Hickey

**Administrative support:** Michelle Peate, Bettina Meiser, Ursula Sansom-Daly, Jennifer Sangster

**Provision of study materials or patients:** Susan Rovelli, Ursula Sansom-Daly, Martha Hickey

**Collection and assembly of data:** Michelle Peate, Ursula Sansom-Daly

**Data analysis and interpretation:** Michelle Peate, Bettina Meiser, Michael Friedlander, Dusan Hadzi-Pavlovic, Martha Hickey

**Manuscript writing:** Michelle Peate, Bettina Meiser, Michael Friedlander, Helen Zorbas, Susan Rovelli, Ursula Sansom-Daly, Jennifer Sangster, Dusan Hadzi-Pavlovic, Martha Hickey

**Final approval of manuscript:** Michelle Peate, Bettina Meiser, Michael Friedlander, Helen Zorbas, Susan Rovelli, Ursula Sansom-Daly, Jennifer Sangster, Dusan Hadzi-Pavlovic, Martha Hickey

## REFERENCES

1. Australian Institute of Health and Welfare (AIHW), Australasian Association of Cancer Registries (AACR): Cancer in Australia 2001, Cancer Series no. 28. Canberra, Australia, Australian Institute of Health and Welfare, 2004
2. Holsapple CW: Knowledge management in decision making and decision support. *Knowledge Technol Policy* 8:5-22, 1995
3. Partridge AH, Gelber S, Peppercorn J, et al: Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol* 22:4174-4183, 2004
4. Thewes B, Butow P, Girgis A, et al: The psychological needs of breast cancer survivors; a qualitative study of the shared and unique needs of younger versus older survivors. *Psychooncology* 13:177-189, 2004
5. Thewes B, Meiser B, Taylor A, et al: Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *J Clin Oncol* 23:5155-5165, 2005
6. Thewes B, Meiser B, Rickard J, et al: The fertility- and menopause-related information needs of younger women with a diagnosis of breast cancer: A qualitative study. *Psychooncology* 12:500-511, 2003
7. Knobf MT: The menopausal symptom experience in young mid-life women with breast cancer. *Cancer Nurs* 24:201-210, 2001
8. Duffy CM, Allen SM, Clark MA: Discussions regarding reproductive health for young women with breast cancer undergoing chemotherapy. *J Clin Oncol* 23:766-773, 2005
9. Biglia N, Cozzarella M, Cacciari F, et al: Menopause after breast cancer: A survey on breast cancer survivors. *Maturitas* 45:29-38, 2003
10. Lee SJ, Schover LR, Partridge AH, et al: American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol* 24:2917-2931, 2006
11. Cassileth B, Zupkis R, Sutton-Smith K, et al: Information and participation preferences among cancer patients. *Ann Intern Med* 92:832-836, 1980
12. Butow P, Brindle E, McConnell D, et al: Information booklets about cancer: Factors influencing patient satisfaction and utilization. *Patient Educ Couns* 33:129-141, 1998
13. Degner LF, Kristjanson LJ, Bowman D, et al: Information needs and decisional preferences in women with breast cancer. *JAMA* 277:1485-1492, 1997
14. Ibbotson T, Maguire P, Selby P, et al: Screening for anxiety and depression in cancer patients: The effects of disease and treatment. *Eur J Cancer* 30A:37-40, 1994
15. Zigmond AS, Snaith RP: The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 67:361-370, 1983
16. Michie S, Dormandy E, Marteau TM: The multi-dimensional measure of informed choice: A validation study. *Patient Educ Couns* 48:87-91, 2002
17. O'Connor AM: Validation of a decisional conflict scale. *Med Decis Making* 15:25-30, 1995
18. Hosmer D, Lemeshow S: *Applied logistic regression*. Toronto, Ontario, Canada, Wiley & Sons, 2000
19. Cohen J: *Statistical Power Analysis for the Behavioural Sciences* (ed 2). New York, New York, Academic Press, 1988
20. Armitage P, Berry G, Matthews J: *Statistical Methods in Medical Research* (ed 4). Oxford, United Kingdom, Blackwell Science, 2002
21. Jukkala AM, Azuero A, McNeen P, et al: Self-assessed knowledge of treatment and fertility preservation in young women with breast cancer. *Fertil Steril* 94:2396-2398, 2010
22. Patient Decision Aids Research Group: *Evaluation Measures*. Ottawa, Ontario, Canada, Ottawa Hospital Research Institute and the University of Ottawa, 2010
23. Collins ED, Moore CP, Clay KF, et al: Can women with early-stage breast cancer make an informed decision for mastectomy? *J Clin Oncol* 27:519-525, 2009

24. O'Connor A, Jacobsen M: Decisional conflict: Assessing and supporting patients experiencing uncertainty about choices affecting their health. Ottawa, Ontario, Canada, Ottawa Health Research Institute, 2003
25. Raynes-Greenow CH, Nassar N, Torvaldsen S, et al: Assisting informed decision making for labour analgesia: A randomised controlled trial of a decision aid for labour analgesia versus a pamphlet. *BMC Pregnancy Childbirth* 10:15, 2010
26. Song M-K, Sereikab SM: An evaluation of the Decisional Conflict Scale for measuring the quality of end-of-life decision making. *Patient Educ Couns* 61:397-404, 2006
27. Rutten LJF, Arora NK, Bakos AD, et al: Information needs and sources of information among cancer patients: A systematic review of research (1980-2003). *Patient Educ Couns* 57:250-261, 2005
28. Commonwealth Department of Health and Aged Care: National Action Plan for Promotion, Prevention and Early Intervention for Mental Health, in *Mental Health and Special Programs Branch*. Canberra, Australia Capital Territory, Australia, Commonwealth Department of Health and Aged Care, 2000
29. Stark DP, House A: Anxiety in cancer patients. *Br J Cancer* 83:1261-1267, 2000
30. Mills M, Sullivan K: The importance of information giving for patients newly diagnosed with cancer: A review of the literature. *J Clin Nurs* 8:631-642, 1999
31. Fallowfield L, Ford SLS: No news is not good news: Information preferences of patients with cancer. *Psychooncology* 4:197-202, 1995
32. NHMRC National Breast Cancer Centre: Clinical practice guidelines for the management and support of younger women with breast cancer. Camperdown, New South Wales, Australia, National Breast Cancer Centre, 2004
33. Donnez J, Kim SS, Albertini DF: Proceedings of the First World Congress on Fertility Preservation: Executive summary. *J Assist Reprod Genet* 27:191-195, 2010
34. Hack TF, Degner LF, Watson P, et al: Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psychooncology* 15:9-19, 2006
35. Keating NL, Landrum MB, Arora NK, et al: Cancer patients' roles in treatment decisions: Do characteristics of the decision influence roles? *J Clin Oncol* 28:4364-4370, 2010
36. Agbarya A, Linn S: The importance of fertility preservation in women with early breast cancer. *J Clin Oncol* 27, 2009 (suppl; abstr e20663)
37. Chambers GM, Ho MT, Sullivan EA: Assisted reproductive technology treatment costs of a live birth: An age-stratified cost-outcome study of treatment in Australia. *Med J Aust* 184:155-158, 2006



#### **Journal of Clinical Oncology: The Ideal Place to Publish Your Research**

- Impact Factor of 17.793: *JCO's* published articles were cited 104,253 times and accounted for fully 9.7% of all oncology journal citations in 2009.
- Rapid Turnaround: *JCO* averages just 9 weeks from final manuscript acceptance to online publication.
- Maximum Exposure: More than 25,000 of the world's leading oncology professionals receive *JCO* and more than 300,000 unique visitors per month visit [jco.org](http://jco.org).
- No Exclusivity Clause: Authors may reproduce or reuse their own material published in *JCO* for educational purposes at no charge.
- Outstanding Reputation: With an acceptance rate of less than 15%, *JCO* publishes only the highest quality manuscripts across all oncology disciplines.
- International Coverage: *JCO* is available globally in 28 countries and in 15 international editions.

To submit a manuscript, visit [submit.jco.org](http://submit.jco.org).



American Society of Clinical Oncology