

LETTER TO THE EDITOR

Development and Pilot Testing of a Fertility Decision Aid for Young Women Diagnosed with Early Breast Cancer

To the Editor:

Breast cancer is the most frequently diagnosed cancer in women of reproductive age. Most women will be offered adjuvant chemotherapy, which increases the risk of infertility and early menopause in up to 70% of women aged ≤ 40 (1,2). Many women report that they were not fully informed of these consequences (3), yet rate the information about fertility and the potential effects of treatment as extremely important (4). There may be interventions available before chemotherapy that may improve the chances of having future children. Consideration of these interventions and the personal, medical, and legal impact is complex (5). Decision aids (DAs) are a well-established method of providing information and facilitating evidence-based and personalized treatment choices (4,6).

We developed a DA that contains a summary of fertility options (Fig. 1), a discussion of breast cancer and female fertility and a series of values clarification exercises (7); these list the advantages and disadvantages of each treatment option and women are asked to rate each treatment option as an overall "leaning" towards or against each option.

The DA was pilot-tested with women diagnosed with early breast cancer between 6 months and 5 years prior, at two major Sydney hospitals. The women were aged 18–40 years (inclusive) and premenopausal at diagnosis with no history of metastatic disease. Thirty women were approached. Seventeen women (57%) completed the questionnaire, one declined participation, one was ineligible, and seven (23%) did either not complete the questionnaire or were not contactable. Data were gathered via a 44-

item questionnaire. The demographic and treatment characteristics of participants are outlined in Table 1.

Desire for (more) children currently and at diagnosis was assessed as was incidence and duration of amenorrhea (Table 2).

Most participants reported having read the DA thoroughly and reported the amount of information (88%) and length (94%) were "about right". All reported that the booklet was clearly presented, informative, easy to read, and useful. All women also reported being satisfied or very satisfied with what they felt was "very" or "quite" balanced information. The DA would have been "very" or "quite" relevant for 94% of participants, and 44% and 31% reported it would have been "very helpful" in reaching a decision about fertility and cancer treatment decisions, respectively. Eighty-eight percent indicated that they would recommend the booklet to others in the same situation.

Women reported that the booklet made them feel "a little" (53%), or "quite a bit sad or upset" (29%). They indicated that the booklet highlighted the potential loss of fertility, raised concerns about the low success of fertility treatments and a diminished ability to breastfeed, and decreased hope for a successful natural conception.

Participants felt their knowledge had improved "a lot" or "quite a bit" with respect to the fertility options available (81%); the pros (75%), and cons (9%) of fertility treatment options; the impact of different cancer treatments on fertility (63%); and the impact of different fertility treatments on cancer treatment (38%), the family (38%), and the future outcome of the disease (44%). The biggest perceived improvement in understanding was on the different fertility options available to women with early breast cancer.

Participants reported feeling "somewhat" (19%), "a little" (38%) or "quite a bit" (13%) "worried or concerned" by reading the booklet, while 31% reported being "not at all worried or concerned."

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Summary of fertility options

	<i>Pregnancy rate</i>	<i>Delay</i>	<i>Availability</i>	<i>Cost</i>	<i>Require sperm</i>	<i>Impact on cancer</i>
Wait & see	Depends on age & treatment	No delay	Not applicable	No cost	No	No impact
IVF	15-20% per cycle	2-6 wks per cycle	Widely available	Costly	Yes	Very little is known*
Egg freezing	1.5% per egg	2-6 wks per cycle	Experimental	Costly	No	Very little is known*
Ovarian tissue freezing	Two live births reported	Short delay	Experimental	Costly	No	Very little is known*
Ovarian Suppression	Not applicable	No delay	Only available through a clinical trial or by prescription	Costly (unless in a trial)	No	Experimental - very little is known*
Adoption	Not applicable	Not applicable	Widely available - but often a long and difficult process	Costly	No	No impact
Egg and Embryo Donation	Egg: 40% Embryo: 15-20% per cycle	No delay	At some clinics	Costly	Only for egg donation	Very little is known*

* Key negative impact on cancer: high dose hormones may impact on cancer and options may cause cancer treatment delays

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Figure 1. Summary of fertility options in the decision aids.

Table 1. Demographic Characteristics (N = 17)

Mean age	
Current	36 years
At diagnosis	33 years
Marital status	
Single	29%
Married or de facto	65%
Separated	6%
Education level	
High school	6%
Certificate/diploma	35%
Undergraduate degree	24%
Postgraduate degree	35%
Cancer treatment	
Surgery	100%
Radiotherapy	53%
Chemotherapy	100%
Endocrine therapy	65%
Fertility treatment	
IVF	47%
Ovarian tissue cryopreservation	6%

When asked to elaborate, women reported that their worry and concern related to the “grim” statistics, the current understanding that they may have reduced fertility, and that the booklet reminded them of an upsetting time in their lives. This may be a result of the anxiety or distress associated with this topic or may reflect that these women were not fully informed at the time of diagnosis. Their current distress may reflect their concern or regret at their lack of knowledge at the time of treatment decision-making. This emphasizes the importance of providing fertility-related information to women as early as possible with the aim of preventing regret post-treatment.

In conclusion, this study highlights the importance of pilot-testing in the clinical setting to ensure the tool

Table 2. Desire for Children and Occurrence of Amenorrhea

Desire for (more) children	Yes	Unsure	No
At diagnosis (n = 17)	77%	17%	6%
Participants with children (n = 8)	50%	25%	25%
Childless participants (n = 9)	89%	11%	0%
Amenorrhoeic (n = 17)	53%		
Average duration (range)	15 (4–48) months		

developed truly addresses the needs of the end users. Pilot-testing of this DA allowed further refinement prior to an ongoing formal prospective evaluation.

Young women with a diagnosis of early breast cancer are confronted with complex decisions that often need to be made prior to commencement of adjuvant treatment. As such, women need to be informed of their treatment options at the earliest possible opportunity. As patients often have difficulty accurately weighing up the benefits and consequences of options that have uncertain outcomes, a decision aid such as ours may provide appropriate decision support for patients to make informed choices. To our knowledge, there are no available DAs that address fertility-related issues and aim to assist the facilitation of fertility treatment decisions in young women diagnosed with early breast cancer. The development of this DA is timely and this pilot study has provided some initial

evidence about the efficacy of the DA in facilitating informed choices about fertility-treatments.

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