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Title: Development and evaluation of a decision aid about fertility preservation for Dutch breast cancer patients : informing patients about fertility preservation
Issue Date: 2014-06-18

Chapter 4

A Delphi consensus study among patients and clinicians on the procedure of informing young breast cancer patients about Fertility Preservation

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Acta Oncologica 2012; 51(8): 1062-69

Abstract

Background The aim of this study was to obtain feedback from, and reach consensus among different experts who are or have been involved in information provision about FP, regarding the (procedure of) information provision about Fertility Preservation (FP) and use of a webbased decision aid (DA) about FP to create optimal conditions for the implementation of the DA-website, as we prepare to implement a DA about FP in the Netherlands.

Methods A two round Delphi study in which experts (patients and clinicians) rated their (dis)agreement with a list of statements (Rounds 1, 2), and additional online forum to discuss dissensus (Round 3). We assessed opinions about FP, web-based DAs, and about the procedure of informing patients. Answer categories ranged from 1 (totally disagree) to 5 (totally agree). Consensus was considered significant when at least 80% of the experts scored either the lowest or the highest two categories.

Results Experts reached rapid consensus on all five statements about the use of a DA (5/5; 100%), and all 8 statements about which patients should be offered information about FP (8/8; 100%). However opinions about FP (4/11 statements; 36%), and procedural aspects such as who should inform the patient (6/10 statements; 60%) and when (3/10 statements; 30%) remained for discussion in round 3. In the online discussion some level of agreement was reached for these statements after all.

Conclusions It was deemed important that FP options exist. Every eligible patient should receive at least some (general) information about FP, soon after diagnosis. Detailed information should be provided by a fertility expert at a later moment. Exact timing and amount of information should be adjusted to patient’s needs and situational context. A DA-website can offer a fair contribution to this.

Background

Due to improved treatment options for young women with breast cancer, survival rates have improved, and quality of life after treatment has became more important. As a result, interest in fertility preservation (FP) has increased in the last decade. In the Netherlands, options for preserving the fertility of women with breast cancer are currently embryo-, ovarian tissue-, and oocyte cryopreservation. Embryo cryopreservation has already been performed routinely for some years, ovarian and oocyte cryopreservation are still experimental.

Information provision about FP is not always sufficient and often late [1-7]. Reasons mentioned for this lack of information are for example related to the experimental character of some of the FP treatments [8;9], ethical issues [10], the difficult timing or the complexity of informing about FP [8;11], and the lack of knowledge about FP [8-10]. Factors associated with withholding information are patient characteristics such as disease stage or prognosis [8;12;13], parental status [8;13], and sexual orientation [12].

Worldwide, there have been some initiatives to improve information provision, by the development of brochures and websites (for example Fertilehope, by the Lance Armstrong Foundation, or Myoncofertility by the Oncofertility Consortium). In order to improve information provision for patients in the Netherlands we also developed a web-based Decision Aid (DA- website) in Dutch about FP for women with breast cancer. The interactive website provides information on different FP options and other ways to fulfill a desire to have children. We assume that a website is a useful method of improving information provision, because it can contain large amounts of information, is accessible at any moment, and can easily be updated to include recent developments. However, before such a website can be implemented in practice, it is necessary to assess experts' opinions about FP, about informing patients about it, and about whether a DA-website could be helpful in improving information provision to patients.

The aim of this study was to obtain feedback from, and reach consensus among different experts who are or have been involved in information provision about FP to create optimal conditions for the implementation of the DA-website, as we prepare to implement a DA about FP in the Netherlands. We assessed their opinions on FP and the possible use of a DA-website, and the procedure of informing patients. We used the Delphi method; a structured process that uses multiple (in this case: 2) rounds of questionnaires to gather information and to reach consensus among participants [14;15]. Furthermore, we used an additional online focus group to explain instances where no consensus was reached in the Delphi rounds.

This paper describes the results of a two round Delphi study and additional online focus group. We report the topics on which the experts reached rapid consensus, and those on which they did not. In those instances where no consensus was reached we explain why this happened. Recommendations are made as to how to embed the results of this study in practice, in order to improve information provision about FP.

Material and methods

Respondents

Respondents were breast cancer patients, breast cancer nurses, oncologists (medical, surgical, and radiotherapy) and gynecologists specialized in fertility issues. Exclusion criteria were no access to the Internet, and insufficient command of the Dutch language (judged by the principal researcher during a telephone call before the start of the study).

Eligible *patients* were female, had received counseling about FP in the past, and had finished their oncologic treatment at least six months ago. Patients were identified through the database of FP patients at the Leiden University Medical Center (LUMC), and approached by means of a personal invitation letter. After two weeks, they were contacted by phone to further explain the study design, and asked for their informed consent. Date and time for this appointment were stated in the invitation letter. All patients who had answered their telephone on the appointed moment were included in the study.

Eligible *clinicians* were nurses and physicians who had completed the appropriate education and were registered as such, who were involved in the treatment of breast cancer patients, who had experience with FP, and who expected themselves to be able to finish all three rounds of the study. They were identified by making use of member lists of special interest groups, Internet searches, acquaintances of members of the project group, and snowballing. We tried to include clinicians from all parts of the Netherlands, and both advocates and opponents of FP (based on previous experiences of the project members with these clinicians). Clinicians were approached by phone and were asked to give informed consent for participation by email.

Beforehand we agreed that the panel should be composed of at least 8 patients, 4 breast cancer nurses, 4 medical oncologists, 2 radiotherapists, 2 surgeons, and 4 gynecologists.

Respondents received a 20-euro incentive for participation. Our study was approved by the Medical Ethical Committee of the LUMC.

Design

An online Delphi study was conducted, consisting of two rounds in which experts rated their (dis)agreement with a list of statements. In an additional online focus group statements for which consensus had not been reached in the Delphi rounds were discussed. Since there are no strict guidelines for the number of rounds in a Delphi study (on average 2-4 rounds), we have chosen for two Delphi rounds in anticipation on the little available time of medical specialists, due to their busy schedules. With the addition of an online focus group we expected to obtain maximal information on dissensus and consensus, with a minimal number of Delphi rounds.

Rounds 1 and 2: Delphi

Round 1 consisted of 48 statements in 6 categories. Statements had been composed by making use of available literature on FP and implementation science, as well as clinicians' and patients' experiences with FP [7-10;12;16;17].

Respondents were asked to rate their (dis)agreement with these statements on a 5-point Likert scale, ranging from 1 (totally disagree) to 5 (totally agree). Demographic and/or practice-related characteristics were also obtained. Respondents had access to the newly developed DA-website.

After Round 1, the degree of consensus was assessed. Consensus on a statement was considered to be reached when at least 80% of the respondents rated either the lowest or highest two categories [18]. This cut-off was chosen because we wanted to achieve the highest consensus possible with both advocates and opponents in one panel (unlikely to be 100%).

Statements for which no consensus was reached were again presented to the respondents in Round 2, together with medians and ranges of the total group responses from Round 1 (Figure 1;[14]). Respondents were then asked to rate their (dis)agreement with the statements in light of others' responses. Furthermore, they were encouraged to provide arguments for their choices.

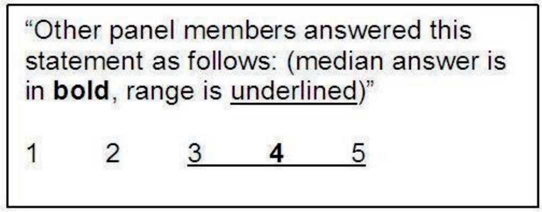
Round 3: Online focus group

Round 3 consisted of an online focus group to discuss statements for which no consensus was reached in previous rounds. These statements had been adapted, based on the open responses of the panel members, to create more vivid discussions (Table 4). When the arguments supplied by participants in Round 2 sufficiently clarified the difference (dissensus) in rating for a particular statement, that statement was not offered for discussion in Round 3.

The online discussion was entirely text-based (forum-like). Panelists were able to login whenever suited them and not necessarily at the same moment. They were not able to see each other, and except for the label "patient" or "clinician", panelists were anonymous in the discussions. Every two days another statement was posted, leaving discussions on previous statements open for comments as well.

Statistical analysis

Medians and ranges are described. Differences in respondents' responses to the statements were tested with Fisher exact tests. All statistical analyses were done using the Statistical Package for the Social Sciences (SPSS) version 17.0.



"Other panel members answered this statement as follows: (median answer is in **bold**, range is underlined)"

1 2 3 **4** 5

Figure 1. Example of the feedback given between Rounds 1 and 2

Results

Participants

We approached 25 clinicians, and 20 patients. Seventeen clinicians were included in the study (response rate 68%; reasons for declining: no time (*n*=5), unreasonable demands for reimbursement (*n*=1), or non-response (*n*=1). One clinician agreed but did not complete rounds 1 and 2 and was excluded afterwards (*n*=1)), and 10 patients (response rate = 50%, 9 declined without stating a reason, 1 had died). The total panel thus consisted of 27 "experts" (Table 1).

Mean age of the patients was 34.4 years old (SD=2.8). Eighty percent of the patients (*n*=8) had a male partner with whom they cohabited. With respect to fertility preservation procedures two patients had chosen to wait and see (20%), five had had cryopreservation of embryos (50%), and three had cryopreservation of ovarian tissue (30%). Two patients had children, of which one before, and one after cryopreservation (without using the cryopreserved material). Nine patients were higher educated (≥15 years of education), one was lower educated (≤10 years of education).

Mean age of the clinicians was 46.7 years old (SD=6.8). They were mostly female (*n*=10, 60%), and had children (*n*=14, 83%). We included clinicians from hospitals in all parts of the Netherlands (North, East, South, West, and Center). Years of clinical experience varied from <1 to >15 years (M=3.8, SD=1.3). Furthermore, the number of breast cancer patients under age 40 they reported to treat annually varied from 1-10 (*n*=8, 47%), 11-30 (*n*=3, 18%), to >30 (*n*=6, 35%).

Table 1. Description of the study population

		Round 1	**Round 2**	**Round 3**
Patients	Patients	10	10	9 (90%)
Clinicians	Medical oncologists	4	4	2 (50%)
	Gynecologists	4	4	3 (75%)
	Radiotherapists	2	2	2 (100%)
	Surgeons	3	3	2 (66%)
	Breast cancer nurses	4	4	3 (75%)
Total	**All experts**	**27 (100%)**	**27 (100%)**	**21 (78%)**

Consensus

Rounds 1 and 2 consisted of respectively 48 and 26 statements. The agreement on the statements is presented, per category and round, in Figure 2, and Tables 2 and 3. For seventeen statements, consensus was not reached in the first two rounds. Sixteen statements were adapted based on open responses of the experts, to form ten statements that were presented in Round 3 (Table 4). For one statement, the arguments supplied by participants in Round 2 already indicated consensus, so these arguments were used to explain dissensus in ratings.

Consensus Round 1

For 22/48 statements (46%) consensus was reached in Round 1 (Table 2).

Experts thought it was important that FP exists, and it was important and acceptable that patients are informed about FP as early as possible. In general, talking about fertility after breast cancer was not thought to give false hope to women. However, based on success rates, experts thought it was only justifiable to offer embryo cryopreservation to patients.

All women in the reproductive age who are at risk of losing their fertility should receive information about FP, independent of marital status, sexual orientation, parity, expressed child wish, and whether women introduced the subject “fertility” or not.

Table 2. Statements that reached consensus in Round 1

	Opinions about FP and DAs	**% disagree**	**% do not know**	**% agree**
1	Talking about fertility after BC gives false hope	100	0	0
2	Success rates of embryo cryopreservation are too low to justify offering it	82	19	0
3	Early information provision about FP is important	96	0	4
4	Offering information about FP upsets patients	96	0	4
5	Offering information about FP would delay BC treatment	89	0	11
6	Offering information about FP can make patients decide not to want BC treatment	96	0	4
7	A website does not contribute to patient education	93	4	4
8	It is important that FP is possible	4	0	96
9	The availability of a website is important	0	4	96
10	Information of the website should be printable	0	7	93
	Which patients should be informed?			
11	Women who already have children	0	4	96
12	All women with breast cancer of fertile age, who are at risk of losing their fertility	7	4	89
13	Lesbian women	0	7	93
14	*Only* women in a steady relationship	93	7	0
15	*Only* women who themselves express their child wish	96	4	0
16	*Only* when a patient brings up the subject "fertility" herself	96	4	0
	By which clinician, and when?			
17	Clinicians should not be forced to offer FP to their patients	96	0	4
18	The website with information about FP should only be offered in hospitals where FP is possible	93	4	4
19	The opinion of a clinician about FP should not matter in offering information about FP to patients	11	0	89
20	The hospitals view about FP should not matter in offering information about FP to patients	7	4	89
21	The best moment to introduce the subject fertility is when the treatment plan is explained	11	7	82
22	The information on the website about FP makes it more easy to talk about FP *for patients*	4	4	93

Furthermore, any personal opinions of clinicians as well as the hospital's general view should not have any bearing on the provision of information about FP to patients.

The availability of the DA-website was regarded as important to inform patients, and to enable patients to talk about FP more easily.

Consensus round 2

Many statements for which no consensus was reached in Round 1 already leaned towards consensus. Nine additional statements reached consensus in Round 2 (Table 3). Experts agreed that the moment at which the information is given to patients should be adjusted to the patient and not to the hospital. Furthermore, women with a poor prognosis for long-term survival should also be informed about FP.

Handing out information (e.g. a DA-website) *after* the consultation with the oncologist, and *before* the consultation with the fertility specialist was thought to save time in both these consultations.

Experts thought the DA-website would decrease the load on patients (e.g. in travel expenses), and would enable clinicians to talk about FP. Questions about FP should be addressed to a fertility specialist.

Round 3 (discussion of dissensus Rounds 1 and 2)

For seventeen statements consensus was not reached after two rounds. Sixteen of these statements were adapted or combined to form 10 new statements for the online discussion (Table 4).

No consensus was reached on whether or not it would be acceptable to give less effective treatment for breast cancer in order to preserve fertility. In Round 2 patients and nurses thought it would not be acceptable (n=7, 50%), while specialists often did not know (n=7, 54%). In the discussion, the majority of the panelists agreed that the acceptability of giving less effective treatment for breast cancer depends on patients' and clinicians' preferences.

It was not clear whether or not FP was promising. Patients and specialists either did not know (n=14, 61%) or agreed that the options were promising (1 disagreed); breast cancer nurses tended to disagree more often (n=2, 50%; p=0.07). Experts stated that it was promising that attention is given to FP, but that FP options as they are now (especially cryopreservation of ovarian tissue and of oocytes) are not very promising. However, it was emphasized that the field of FP is developing quickly, and that the options can *become* promising. Decisions about FP should be based on qualitatively good information, and on weighting the pros and cons of each FP option. Discussion among the experts revealed that informing patients about ovarian tissue- and oocyte cryopreservation is acceptable as long as no false hope is given, and low success rates are communicated to patients.

It was difficult to establish the best moment for informing patients. Experts stated that information should be provided as soon as possible. This does not have to be at the time of diagnosis; as long as it is no later than the moment the treatment plan is discussed with the patient. Furthermore, the information should be adjusted to the patient's informational needs at that moment.

Table 3. Statements that shifted towards consensus in Round 2

		Delphi round	% disagree	% do not know	% agree
	Attitude DA				
1	A website will decrease the load on patients (e.g. in travel expenses)	1	19	15	67
		2	7	7	85
2	The website should be generalized to other types of cancer	1	15	22	63
		2	4	4	93
	Procedure- which patients should be informed, by which clinician, when?				
3	Only patients with a prognosis for long-term survival (>50%)	1	78	15	7
		2	85	7	7
4	Patients should address questions about FP to a gynecologist/ fertility expert	1	7	19	74
		2	4	4	93
5	Timing of the information about FP should be adjusted to the patient	1	26	15	59
		2	11	7	82
6	Timing of the information about FP should be adjusted to the hospital	1	74	15	11
		2	82	11	7
7	Giving information about FP prior to the consultation with the gynecologist/fertility clinician saves time in the consultation	1	11	15	74
		2	4	11	85
8	The possibility to refer patients to a website would save much time in the consultation with the oncologist	1	15	19	67
		2	7	7	85
9	The information on the website about FP makes it more easy to talk about FP *for specialists*	1	0	33	67
		2	0	7	93

FP=fertility preservation

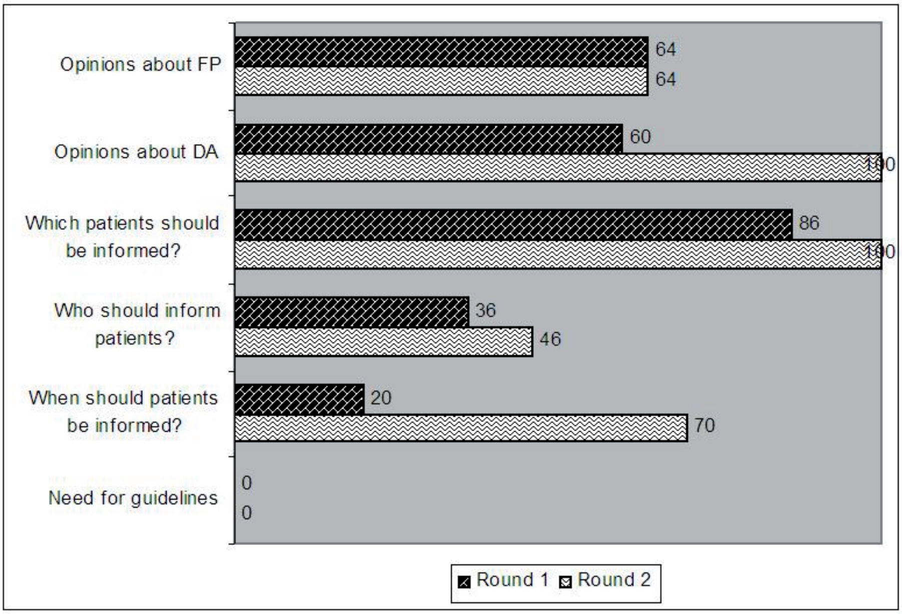


Figure 2. Percentage of concensus per category, Rounds 1 and 2

There was much ambiguity about which clinician should inform patients about FP and to whom patients should address questions about FP. It appeared that there is no single type of clinician who should inform patients and be available for questions. Moreover, a distinction was made between introducing the subject and providing more detailed information. In the discussion, experts agreed that the introduction of the information (or referral to a website) can be done by any health professional, as long as detailed information about FP is given by an FP expert at a point in time not too much later.

When patients have already been in contact with a fertility expert, they can address questions about FP to that person. If not, patients should address their questions to an oncologist, nurse, or other specialist in the (multidisciplinary) breast cancer team who can refer them on to more specialized staff.

Many patients were in favor of using the DA-website in the consultation with the fertility specialist. Specialists and breast cancer nurses mentioned that this depends on the clinician’s preference.

Seventy-eight percent of the experts agreed that guidelines are needed to structure the procedure for informing patients. However, it was unclear which specific procedural aspect this concerned, and whether guidelines should be local or national.

Forty-seven percent of the clinicians thought their clinic did not provide enough information about FP at present (*n*=8).

Table 4. Statements for the online discussion in Round 3

	Statements
1	The fertility preservation options are promising
2	The success rates of experimental treatments such as cryopreservation of ovarian tissue and oocytes are too low to justify offering it to patients
3	It is acceptable to give a less effective treatment for BC to preserve fertility
4	The information about FP can be introduced by anyone
5	Detailed information about FP should only be given by a gynecologist or fertility specialist
6	As soon as it is known that a patient is eligible for FP because of a risk of infertility due to treatment for breast cancer, it is important to introduce the options soon
7	Detailed content information about FP can be given later on to the patient, by a FP specialist
8	Patients should address questions about FP to their treating oncologist
9	When patients have already seen a fertility specialist they should address their further questions to this specialist
10	A checklist and clear agreement about the procedure of informing patients about FP for each medical center is better than a national guideline

Discussion

A Delphi study with online discussion was conducted with experts involved in information provision about FP, to reach consensus on (the procedure for) informing patients about it. Experts thought it was important that every eligible woman receives clear, objective information about FP. General information should be introduced soon after diagnosis (by any health professional), and details later on (by a fertility expert).

As expected, experts valued the more experimental FP treatments differently from embryo cryopreservation [9] There was no consensus on whether or not cryopreservation of oocytes and ovarian tissue could justifiably be offered (8% pro, 76% contra). This is comparable to findings from Kohler et al (2011) who found that only a minority of oncologists (46%) agreed that all pubertal females (13-18 years of age) should be offered ovarian tissue cryopreservation [7]. The experimental character of FP has been found to be a barrier to informing women [8;9], but experts in our study thought that patients should be informed about all options (incl. experimental ones), as long as the information is objective and complete.

Interestingly, different experts made different value trade-offs when formulating their opinions about FP. This underlines that the decision about whether or not to undergo FP is a preference-sensitive decision [19]. The literature suggests that preference-sensitive decisions should be based on good quality information, and on weighting the pros and cons and patients' values [19]. Similar suggestions were mentioned by the experts.

Experts agreed that it is important that all eligible patients are informed about FP. However, similar to many other studies [1-7], 47% of the experts indicated that the information their clinic provides about FP is insufficient at present. A majority of panelists welcomed guidelines to structure the information provision about FP, but they were unable to indicate for which procedural aspects. Increased knowledge of FP among medical professionals in terms of information provision may therefore be more important than in terms of structuring the information provision. With the involvement of patients and clinicians in this study we hope to have created awareness, and thereby supported the implementation of a DA about FP that we have developed.

Panelists reached rapid consensus that *all* women of reproductive age who are at risk of treatment-induced infertility should receive information about FP. Similar to Kohler et al (2011), none of the barriers mentioned in previous literature [8-13] held true for our experts [7]. However, these studies were conducted in 2007-2009, so it is possible that these barriers were resolved by time.

The DA-website was thought to decrease the load for patients (e.g. in travel expenses), to enable patients and clinicians to talk about FP, and to save time in the consultation with the oncologist (who introduces the subject and refers to the website) as well as with the fertility specialist (who has less explaining to do). In previous studies, DAs have been found to be helpful in involving patients more actively [20], and to decrease the length of a counseling consultation when given *prior* to counseling [21]. Experts mentioned that specialists could use the DA-website *in* the consultation as well, but they should decide for themselves whether or not they would like that.

Regarding the issue of who should inform patients, experts distinguished between introducing the information and providing detailed counseling. The available literature and guidelines have suggested a role for oncologists [16;22], gynecologists [16], or (oncologic) nurses [23] in informing women about FP. Panelists suggested a role for oncologists and nurses in introducing the information, and for fertility experts in providing more detailed counseling.

Some limitations have to be taken into account when interpreting these results. We defined consensus at 80% agreement. Most other recent studies have used lower margins, varying from less than 30% in both scale ends [24], to 80% [18]. If we had used a lower margin, more statements would have reached consensus early in the Delphi process (since the least "agreement" we found was 47%), so we would not have been able to obtain experts' considerations in formulating their opinions, as we have been now. Despite our efforts to include both opponents and advocates of FP, most experts were in favor of FP. With our strict definition of consensus we were nevertheless able to distinguish opposing opinions to some extent. Some statements did not reach consensus because they were not stated sufficiently explicitly for the experts. In the online discussion we were able to obtain consensus on these statements anyway. It is unclear what caused the shifts in opinion between rounds: the opinions of others, or simply participation in this study that caused experts to think more thoroughly about it. Lastly, 78% (*n*=21) of the experts participated in Round 3. Experts who remained active had possibly more affinity with FP or may have had more time to actively participate in an online discussion. It would be interesting to know the opinions of the more busy clinicians, because attention to FP is important in busy schedules as well.

In conclusion; it is important that every eligible woman receives qualitatively good information about FP soon after diagnosis, in order to have enough time to make a decision regarding FP. The exact procedure for informing women should be adjusted to patients' informational needs as well as the local situation. The web-based DA about FP that we have developed can contribute to this information provision.

Future research should focus on evaluating the effectiveness of the DA-website for newly diagnosed patients who have to decide on FP. Furthermore, since this website is meant for patients and not clinicians, it could be valuable to increase clinicians' knowledge about FP as well, and make sure they have up-to-date information about FP to help their patients decide.

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