

Cover Page



Universiteit Leiden



The handle <http://hdl.handle.net/1887/26934> holds various files of this Leiden University dissertation

Author: Garvelink, Mirjam

Title: Development and evaluation of a decision aid about fertility preservation for Dutch breast cancer patients : informing patients about fertility preservation

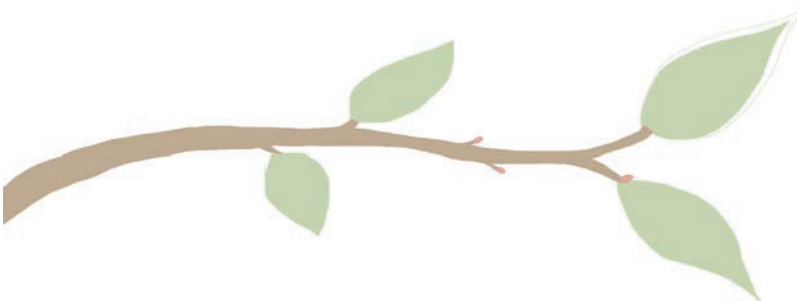
Issue Date: 2014-06-18

Chapter 5

Values Clarification in a decision aid about fertility preservation:
does it add to information provision?

Mirjam M. Garvelink
Moniek M. ter Kuile
Anne M. Stiggelbout
Marieke de Vries

(Submitted, 2013)



Abstract

Background To improve information provision and decision making about fertility preservation for breast cancer patients, a web based decision aid (DA) with values clarification exercise (VCE) was developed. We aimed to evaluate the effect of a DA with information only compared to a DA with VCE, and to study the relation between personality and information seeking style on DA-use, decisional conflict and knowledge.

Methods Two scenario-based experiments were conducted with two different groups of healthy female participants. Dependent measures were: decisional conflict score (DCS), knowledge, and DA-use (time spent, pages viewed, VCE used). Respondents were randomized between a DA with information only (VCE-) and a DA with information plus a VCE (VCE+) (*experiment 1*), or between information only (VCE-), information plus VCE without referral to VCE (VCE+), and information plus a VCE with referral to VCE (VCE++) (*experiment 2*). In experiment 2 we additionally measured personality (neuroticism/conscientiousness) and information seeking style (monitoring/blunting).

Results *Experiment 1.* There were no differences in DCS, knowledge or DA-use between VCE- (n=70) and VCE+ (n=70). Both DAs lead to a mean gain in knowledge from 39% at baseline to 73% after viewing the DA. Within VCE+, VCE-users (n=32, 46%) reported less DCS compared to non-users. Since there was no difference in DCS between VCE- and VCE+, it is unlikely that the VCE caused this difference. *Experiment 2.* There were no differences in DCS or knowledge between VCE-(n=65), VCE+ (n=68), VCE++ (n=66). In all groups, knowledge increased on average from 42% at baseline to 72% after viewing the DA. Blunters viewed less DA-pages ($R=0.36$). More neurotic women were less certain ($R=0.18$) and felt less supported in decision making ($R=0.15$); conscientious women felt more certain ($R=-0.15$) and had more knowledge after viewing the DA ($R=0.15$).

Discussion Results indicate that (the information on) both DAs leads to increased knowledge in healthy populations making hypothetical decisions, but that use of the VCE does not seem to improve knowledge or decisional conflict. Personality characteristics were slightly associated with DA-use, information seeking styles with aspects of decisional conflict.

Background

Preference sensitive decision making

An increasing number of medical decisions are preference sensitive, indicating that the “best” decision or treatment option does not only depend on what is best from a medical point of view, but depends on patient preferences with regard to the treatment options as well, and should therefore take into account the values a patient attaches to the advantages and disadvantages of those option(s). In other words, with preference sensitive decisions, patients should be actively invited to participate in decision making [1-3].

Decision aids (DAs)

In order to increase participation in decision making and improve decision making processes and outcomes for preference sensitive decisions, decision aids (DAs) are increasingly used. DAs are tools that provide at minimum some information about the (medical) problem, possible solutions, including an option to wait and see, information about risks and uncertainties, and a balanced overview of advantages and disadvantages of each option[4].

Despite availability of quality criteria for the development and evaluation of DAs [5], which are used by most DA developers, DAs differ with regard to the type of medium (e.g. brochures, booklets, DVD's, CD-ROMs, websites), their content, and the offered decision making support [6-8]. Some DAs provide patients with information only, summaries, or patient narratives, with which patients can implicitly clarify what is important for them. Others combine information with explicit values clarification methods (VCM), in which patients are supported in active deliberation about what is important to them.

In general, DAs as a whole have been found to be effective in reducing decisional conflict, increase knowledge on the subject, lead to more realistic expectations, and to lead to a higher percentage of patients who are able to decide on a course of action [4]. However, the effect of specific aspects, such as VCMs (if effective at all) is less clear [4;7;9-12]. Two patient studies that have evaluated the effect of DAs with several types of VCM compared to DAs without VCM or information only, did find that VCMs in the form of an explicit values clarification exercise (VCE) lead to a higher percentage of patients who made an informed decision that was in agreement with their personal values [4], a higher congruence between values and treatment [4], and lead to feeling better prepared for decision making [13]. One scenario based study in healthy participants found no significant beneficial effects of VCMs compared to information only [10], one did [7]. When comparing explicit with implicit VCM [7;12], explicit VCM were more effective in healthy participants [7], but no improvements were found in patient populations [12]. Additionally, in theory, deliberation (with VCM) and analytical reasoning may not always be beneficial for decision making [11], since deliberation may overshadow important intuitive feelings that are more difficult to formulate but may be just as important in decision making[11].

The decision

A good example of a preference sensitive decision with a difficult decision making process is the decision whether or not to undergo fertility preserving procedures (fertility preservation, FP) before the start of the cancer treatment when diagnosed with breast

cancer. The last decades, chemotherapy for breast cancer has increased survival chances, but with an increased possibility of losing fertility as a consequence [14]. Since many young cancer patients have a future child wish, interest has risen in possibilities to preserve fertility before undergoing cancer treatment. At this moment one can try to spare fertility by cryopreserving embryos, oocytes, or ovarian tissue [15]. However, since chances to become infertile are never 100%, not undergoing any fertility sparing treatment (wait and see) is also an option [14;16]. All these FP options come with risks and success rates [15;16]. For some years, FP is offered to young women with breast cancer (18-40 years old). Not only are there many aspects to consider in deciding about FP, but the decision also has to be made in the short time frame (often a few days to a week) between diagnosis and start of the chemotherapy treatment, with competing demands from other breast cancer-related decisions and emotions [17].

In order to assist decision making about FP, we have developed a DA for women with breast cancer who have to decide about FP treatments [18]. The DA consists of information, and a fine grained, explicit VCE. The VCE consists of statements about the consequences of each FP option, for which patients are asked to indicate the extent to which they were considered a benefit or disadvantage. Additionally, patients have the option to add arguments and rate these as well. After rating the importance of the separate statements, the DA generates a summary that provides an overview of patients' answers in descending order from most important to least important (as indicated by the patient). Moreover, patients can indicate the extent to which they are in favor of the treatment options, and make a decision based on their own values. Patients are not provided with a clear-cut advice about which treatment to choose. The effect of DAs with VCEs on decision making is largely unknown. We hypothesized that the use of our DA with VCE in deciding about FP would decrease decisional conflict compared to information only [7;13].

Emotions, coping styles and personal characteristics may influence decision processes and the extent to which informational sources are used [19-22]. Since patients may react with feelings of anxiety and depression to the news about a diagnosis with a life threatening disease such as breast cancer and the prospect of a fertility threatening cancer treatment [23-25], it may be important to acknowledge these emotions. Furthermore, emotions may affect values related to the decision, and risk perception [26]. Additionally, patients may have their own coping styles when it comes to getting informed about threatening medical situations, which is reflected in their preferred role in decision making and consequently their behavior with regard to seeking information. For example, patients with monitoring coping styles have been found to ask more questions in the consultation, and to prefer more detailed information [27]. Moreover, it has been suggested that patients with a more neurotic personality preferred less participation in decision making about treatment, while more conscientious patients preferred more participation and deliberation [28]. We therefore hypothesized that having a monitoring coping style or a more conscientious personality would be associated with more extensive use of the DA and VCE, less decisional conflict, and more knowledge after viewing the DA. Blunting coping styles and neurotic personalities were thought to be associated with less use of the DA and VCE, more decisional conflict and less knowledge after viewing the DA.

The current research

In order to test the above mentioned hypotheses, two experiments were performed with healthy participants making hypothetical decisions about FP. In order to make participants more similar to patients, we have induced them with neutral, sad and anxious emotions. Although we are well aware of the limitations of including healthy participants instead of patients we chose for healthy participants to be able to include enough participants to reach sufficient power. Additionally, we thought it would be unethical to test these specific hypotheses in a patient population, before they were tested hypothetically in non-patients.

In experiment 1 we studied the effect of type of DA (information only versus information+VCE) on DA-use, decisional conflict, and knowledge. Additionally we assessed the effect of VCE-use on decisional conflict and knowledge.

In experiment 2 we assessed associations between several personality characteristics and information seeking styles with the extent to which the DA was used and on decisional conflict and knowledge.

Experiment 1

Methods

Study design

The study was a 2 (type of DA: DA with information only or DA with information and a VCE) by 3 (emotion: neutral, anxious, or sad) between subjects factorial design, stratified by location (Leiden University – location 1, Tilburg University – location 2). The DA with information only consists of textual information (consisting of 20 separate webpages) and the DA with VCE additionally consists of a VCE for each FP option (consisting of six separate webpages).

Participants

Participants were healthy women between 18-36 years old ($M=20.8$, $SD=3.4$), who had sufficient understanding of the Dutch language. Participants were invited by advertisements at universities, in libraries and on websites (including social media). Participants participated in exchange for either money (location 1; 8 euros) or course credits (location 2). Participants at location 1 had to actively approach the researcher and had to make an appointment to participate. Participants at location 2 could easily subscribe through an online system.

Procedure

Measurements

The study was completely computerized, outcomes were measured with questionnaires and web statistics. All measures were measured immediately after viewing the DA, except for knowledge which was measured both before and after viewing the DA.

The primary outcome measure was decisional conflict. This was measured with a Dutch translation of the decisional conflict scale (DCS) (including the subscales values clarity, informed decision making, effective decision making, decision making support, decision making uncertainty) [29]. The total scale consists of 16 items measured on a

5 point Likert scale ranging from 0 (totally disagree) 4 (totally agree). A total decisional conflict score is obtained by adding up the scores on the items, dividing them by the number of items and rescaling them from 0-100. A higher score on the DCS, or one of its subscales, indicates more decisional conflict.

Other outcomes were knowledge about FP, measured with 10 statements about FP options with the answer categories “true”, “false”, or “I do not know”. Furthermore, we measured preferred FP option (5 categories: wait and see (not undergoing a fertility sparing treatment), cryopreservation of embryo’s, oocytes, ovarian tissue, do not know), socio-demographic characteristics (age, child wish, parity, experience with (breast) cancer in relatives and peers, relational status, cohabiting, education, ethnicity, religious affiliation), and web statistics such as total time spent on the DA and number of informational- and VCE-pages viewed.

Emotion induction

Emotions were induced by a combination of a short film fragment and background music during the entire experiment, two methods that have previously been found to be successful for inducing moods[30].

Directly after emotions were induced, respondents read a hypothetical script in which they were asked to imagine that they were at a consultation with their oncologist and just received the diagnosis of breast cancer, for which they would be treated with chemotherapy. Since chemotherapy might influence their fertility, they are offered the chance to preserve their fertility before undergoing chemotherapy. At the end of the script women were referred to a DA website to prepare them for making a decision. Respondents were then actually referred to the DA. They were instructed to spend as much time, and view as many pages on the DA as they thought was necessary to make a decision, there was no minimum or maximum.

In order to test whether the emotion induction was successful, participants were asked before (pre induction - I), immediately after emotion induction and after reading the script (post induction - II), and after viewing the DA (post DA - III), to what extent they felt happy, anxious and sad at that moment on a 7-point Likert scale (i.e. “to what extent do you feel happy at this moment”?). This emotion manipulation check indicated that all participants felt more sad ($\Delta M = 2.1$) and anxious ($\Delta M = 2.1$) after induction, and less happy ($\Delta M = -2.0$). No differences were observed between the three emotion induction conditions. Likely, the hypothetical script, which all participants had to read following the emotion induction and before measurement of emotions, and the decision itself, may have evoked feelings of sadness and anxiety in all participants. Since no differences on perceived emotions were found between emotion induction conditions, we controlled for emotion induction condition in all analyses but no further analyses were conducted with emotions.

Statistics

Analyses were conducted with SPSS 20.0. Differences between the DAs in continuous outcomes with only one measurement moment (e.g. DCS,) were tested with one-way ANOVAs with DA-type (VCE +/-) as between-subjects factor. Differences in knowledge scores at baseline and after viewing the DA were tested with a General Linear Model

(GLM) for repeated measures, with DA-type (VCE +/-) as between-subjects factor. Since not all participants randomized to information plus VCE actually used the VCE, we conducted secondary analyses with a new grouping variable, consisting of three arms: information only (VCE-), information plus a VCE which was not used (VCE+-), and information plus a VCE which was used (VCE ++). This variable replaced the fixed variable “DA-type” in the ANOVA and GLM for repeated measures as described above. All the analyses were done, while controlling for the effect of emotion induction condition and location.

Power calculation

A sample size of 64 participants per treatment arm was considered sufficient to analyze main effects on decisional conflict with a power of 0.8 (Cohen’s $d=0.5$; $\beta=0.2$; $\alpha=0.05$). Within the two DA-conditions respondents were equally randomized among the three different emotion conditions.

Results

Participants and socio-demographic characteristics

One-hundred fifty-one women participated. We excluded 11 women because of incomplete data on main outcomes due to problems with internet or the questionnaire. The total population used for data analyses consisted of 140 participants, 39 in location 1, and 101 women in location 2.

At baseline there were no differences in socio-demographic characteristics between the locations (data not shown). Furthermore, randomized conditions (DA-types) were comparable on most socio-demographic characteristics. With regard to child wish (for the future) we found that women in the information only condition somewhat less often had a child wish than women in the VCE+ conditions ($\chi^2=7.17$, $p<.01$; Table 1).

Effect of type of DA on decision making, DA use, decisional conflict, knowledge

Of the total population, 114 women (81%) were able to make a decision whether or not to preserve fertility, of which 24 women (21%) wanted to wait and see, and 90 women (79%) chose to cryopreserve either embryos ($n=45$), oocytes ($n=34$) or ovarian tissue ($n=11$).

There were no effects of DA-type (information with or without VCE) on time spent on the DA or number of pages viewed (Table 1). Mean number of pages viewed for the total group was 13.4 ($SD=7.7$) and mean time spent on the DA was 8.9 minutes ($SD=7.9$). The correlation between time spent on DA and pages viewed was high ($r=.75$, $p<.001$), therefore we chose to use only “time spent” in further analyses.

There were no significant differences in decisional conflict scores (including scores on all subscales) or knowledge between women who received the DA with information only (VCE-) or with information and a VCE (VCE+) (Table 1). In both conditions, the DA led to a significant increase in knowledge ($F(1, 127)=264.96$, $p<.001$). At baseline, mean knowledge score for the total group was 4.2, after viewing the DA it was 7.6; a relative increase of 81%. Moreover, after adjustment for baseline knowledge there was a significant positive relation between knowledge after viewing the DA and time spent on the DA ($r=0.33$ $p<.001$).

Effect of using the VCE on total DA use, decisional conflict

Of the women in the VCE+ condition ($n=70$), only 33 women (47%) had viewed the VCE (VCE++, table 1). These women spent on average 2.49 minutes (range 10 seconds – 8 minutes) on the VCE. There was a significant difference in time spent on the DA between women who did or did not use the VCE ($F(2,122)=9.01, p<.001$). Women who had used the VCE spent more time on the DA than women who did not.

There was a significant difference between women who received information only (VCE-), and those who received a DA with VCE and did (VCE++) or did not (VCE+-) use the VCE, with regard to decisional conflict ($F(2, 122)=6.4, p<.01$), values clarity ($F(2,122)=9.4, p<.001$), and informed decision making ($F(2, 122)=3.2, p<.05$). Women who used the VCE reporting the best (lowest) scores, followed by women who received information only (who were not able to use the VCE); women who were able to but did not use the VCE reported the worst (highest) scores. Furthermore, women who had used the VCE reported better (lower) scores on effective decision making ($F(2, 122)=4.4, p<.05$) and decisional support ($F(2, 122)=3.4, p<.05$) than those who did not use it (Table 1).

Conclusion experiment 1

Experiment 1 showed no difference in knowledge or decisional conflict between women who received a DA with or without a VCE. Secondary analyses within women who received a DA with VCE revealed less decisional conflict for women who *used* the VCE compared to those who did not use it, but with no certainty that it was the VCE that caused this difference, since there was no difference when VCE-users were compared to women who received a DA with information only (without VCE).

Table 1. Socio-demographic characteristics, differences in decision-making, decisional conflict, knowledge and DA use between women who received a DA with information only or a DA with information and an explicit VCE (subdivided by whether they used the VCE or not), controlled for emotion induction condition

	DA with information only (VCE-)	DA with information plus VCE (VCE+)		F- (condition) or χ^2 -value	Post hoc analysis
	Total Group VCE- (N= 70)	Total Group VCE+ (N= 70)	VCE used (VCE++) N=33	VCE not used (VCE+-) n= 37	
Age, Mean (SD)	20.7(3.3)	20.9 (3.5)	20.4(3.5)	21.6(3.5)	1.3
Child wish, yes, n (%)	56(80)	64 (91)	34(91)	30(91)	7.17*
Children, yes, n (%)	3 (4)	-	-	-	-
Partner, yes, n (%)	34(49)	42 (60)	24(65)	18(55)	2.59
Decisional conflict					
Total DCS, Mean (SD)	40.9 (11.6)	43.6 (14.2)	37.9 (15.7)	48.6 (10.6)	6.4**
Values clarity, Mean (SD)	27.7 (14.5)	32.0 (18.4)	22.7 (16.4)	40.3 (16.1)	9.4**
Decisional support, Mean (SD)	44.7 (14.2)	45.9(16.7)	38.4 (18.2)	52.7 (11.9)	3.4*
Effective DM, Mean (SD)	32.8(15.7)	33.6 (18.7)	27.3 (19.9)	39.2 (15.9)	4.4*
Uncertainty, Mean (SD)	36.6 (17.8)	40.3 (16.8)	40.9 (20.3)	39.8 (13.2)	0.97
Informed DM, Mean (SD)	65.2 (22.6)	69.6 (22.9)	64.1 (26.6)	74.5 (17.9)	3.1*
Knowledge					
Knowledge post DA, Mean (SD)	7.3 (1.9)	7.2 (1.7)	7.4 (1.7)	6.9 (1.8)	0.36

*=p<0.05 **=p<0.01. VCE-=DA with information only; VCE+= DA with information and VCE; VCE+-=DA with information and VCE, VCE not used; VCE++=DA with information and VCE, VCE used. Δ some pages were viewed repeatedly by the respondents.

(table 1 continued)	DA with information only (VCE-)		DA with information plus VCE (VCE+)		F- (condition) or χ^2 - value	Post hoc analysis
	Total Group VCE- (N= 70)	VCE used (VCE++) N=33	Total Group VCE+ (N= 70)	VCE not used (VCE+-) n= 37		
Time spent (seconds)						
Total time spent, Mean (SD)	510.2(443.9)		558.9(506.9)	856.3 (551.9)	293.6(261.6)	VCE->VCE+<VCE++
Time spent on information only, Mean (SD)	510.2(443.9)		499.3 (436.5)	706.6 (481.7)	293.6(261.6)	VCE->VCE+<VCE++
Pages viewed Δ	12.5 (2-38)		14.4 (3-36)	21 (9-36)	8.5 (3-17)	VCE+<VCE++
Made a decision, yes, n (%)	56 (80)		58 (82.8)			

*=p<0.05 **=p<0.01. VCE-=DA with information only; VCE+= DA with information and VCE; VCE+-=DA with information and VCE, VCE not used; VCE++=DA with information and VCE, VCE used. Δ some pages were viewed repeatedly by the respondents.

Experiment 2

Since experiment 1 showed a beneficial effect of VCE-use on decisional conflict within women who received a DA with VCE, but not when compared to women who received information only, we were interested in finding explanations for this difference. In the first experiment, only a minority of respondents who received a DA with VCE, accessed the VCE. Since no emphasis was put on the availability of the VCE in their DA, it is possible that some did not see the VCE. Therefore, to increase the number of VCE-users in Experiment 2, we added a third condition to the experiment: information plus VCE, with explicitly referring to the VCE. Furthermore personality characteristics were measured to investigate whether DA- and VCE-use and effectiveness of DA- and VCE-use were associated with certain personality characteristics.

Methods

Study design

Participants were randomly assigned to a DA with information only (VCE-), a DA with information and a VCE without referring to the VCE (VCE+), and a DA with information and a VCE with explicitly referring to the VCE (VCE++), stratified by location (Leiden University – location 1, Tilburg University – location 2).

Participants

Participants were healthy women between 18-32 years old ($M=21.4$), with sufficient understanding of the Dutch language. Participants were invited by advertisements at the same universities of experiment 1. Participants participated in exchange for either course credits/hours or money (6 Euros) at both study locations.

Procedure

The study consisted of two parts. Part I consisted of completing questions about personality and information seeking style. Part II consisted of reading a hypothetical script (see experiment 1) after which respondents viewed a version of the DA (according their randomization) and completed questionnaires related to their decision making (process). Both parts were presented as independent studies of different researchers.

Measurements

Measures were as in experiment 1, with addition of the following scales:

Information seeking styles were measured with a short version of the Threatening Medical Situations Inventory (TMSI) of Miller, 1987 [31], after the example of Ong et al [27]. Respondents were asked to read two hypothetical situations (1-vague suspicious headache complaints and 2-choosing for uncertain heart surgery) and complete three monitoring and three blunting items on a five point Likert scale ranging from 1-5 (not at all to strongly applicable to me) for each scenario. Total monitoring and blunting scores were calculated by adding up all relevant items.

Personality traits were measured with the neuroticism (8 items) and conscientiousness subscales (9 items) of the Dutch translation of the Big Five Inventory [32]. Participants were asked to rate their agreement with statements about their perception of themselves in varying situations, on a five-point Likert scale ranging from 1 (strongly disagree) to 5

(strongly agree). Total scores were calculated by adding up all relevant items, dividing by the total number of items per scale.

Statistics

Differences in knowledge scores at baseline and after viewing the DA were tested with a General Linear Model (GLM) for repeated measures. Differences in other continuous outcomes were tested with ANOVAs. Associations between personality characteristics and DA-use were studied with Pearson's product moment correlations (PPMC) and GLMs. All the analyses were done, while controlling for the effect of location.

Power calculation

Presuming a medium effect size ($f=0.25$), we needed a total of 179 participants in three groups to reach a power of 0.8 ($\alpha=0.05$, $\beta=0.2$, with 1 covariate).

Results

Participants and socio-demographic characteristics

One hundred ninety-nine eligible women participated. Due to missing data on some questions, the total population used for data analyses consisted of 197 participants, 91 women in location 1, and 106 women in location 2.

At baseline, there were no significant differences with regard to socio-demographic characteristics between conditions. Mean age of the respondents was 21.4 years old (range 18-32), 179 women (90%) had a future desire for children, and nobody had children.

Effect of type of DA and VCE-use on decision making, DA use, decisional conflict, knowledge

One hundred fifty-two women (77%) were able to make a decision whether or not to preserve fertility, of which 31 (20%) women wanted to wait and see, and 121 (80%) women chose to cryopreserve either embryos ($n=67$), oocytes ($n=47$) or ovarian tissue ($n=7$).

There were no differences between the 3 conditions in total time spent on the DA and the extent to which the informational pages were used (Table 2). However, we did find differences in the extent to which the VCE was used; women who were referred to the VCE significantly more often used the VCE ($F(2,129)=3.8$, $p<.05$), viewed more VCE pages ($F(2,129)=9.6$, $p<.001$), and spent more time on the VCE ($F(2,129)=5.6$, $p<.01$) than women in the VCE+ condition who were not referred.

Of the women in the VCE+ conditions (with and without referral, $n=134$), 84 viewed the VCE (63%). Women who made use of the VCE spent more time on the total DA ($F(2,130)=17.9$, $p<.001$), and on the informational pages of the DA ($F(2,130)=5.8$, $p<.01$) and viewed more informational pages ($F(2,130)=8.7$, $p<.001$) than those who did not, indicating that they used the whole DA more thoroughly.

No significant differences were found between randomization conditions with regard to decisional conflict (or subscales of the DCS)(Table 2). Additionally, within VCE+ (with and without referral), there were no significant differences in DCS or any of the subscales between women who did (VCE++) or did not use the VCE (VCE+-), indicating that VCE-use was not related to differences in decisional conflict between the conditions (Table 2).

Use of the DA lead to a relative increase in knowledge of 71% ($M=4.2$ to $M=7.2$) in the total population ($F(1,193)=20.9$ $p<.001$). No differences in knowledge were found between the randomization conditions, or between women who did or did not use the VCE. Moreover, after adjustment for baseline knowledge score there were significant positive relations between knowledge after viewing the DA, time spent on the DA ($r=.38$ $p<.001$), and time spent on the informational pages ($r=.36$, $p<.001$).

Effect of personality characteristics and information seeking style on DA use, decision making, decisional conflict and knowledge

Personality characteristics and information seeking styles were equally distributed (Table 2). Blunting (with regard to information seeking) was associated with viewing less informational pages ($r=-.36$, $p<.001$) and less total pages ($r=-.29$, $p<.001$). None of the personality traits were significantly associated to the extent to which the DAs were used (time spent, pages viewed). With regard to decisional conflict, being more neurotic was associated with a more decision making uncertainty ($r=.18$ $p<.01$), and decision making support ($r=.15$, $p<.05$) and being more conscientious was associated with less decision making uncertainty ($r=-.15$, $p<.05$). None of the information seeking styles were associated with aspects of decisional conflict.

Knowledge after viewing the DA was associated with more conscientious personality ($r=.15$, $p<.05$) and more monitoring information seeking style ($r=.15$, $p<.05$) (corrected for baseline knowledge).

Table 2 Differences in decision-making, decisional conflict, knowledge and DA use between women who received information only or information plus VCE (subdivided by referral to the VCE, and use of the VCE) (n=197)

	Information plus VCE (VCE+)										Post hoc analysis						
	(N=134)					with referral (n=66)											
	no referral (n=68)					with referral (n=66)											
Information only n=65 VCE-	A	VCE not used n=33 VCE--	B	VCE used n=35 VCE++	C	Total (no referral)	D	VCE not used n=17 VCE--	E	VCE used n=49 VCE++	F	Total (with referral)	G	VCE not used n=49 VCE--	H	Total VCE used n=84 VCE++	I
Time spent (sec)	464 (333)	362 (387)	669 (360)	669 (360)	520 (401)	520 (401)	287 (303)	663 (407)	566 (416)	363 (387)	363 (387)	665 (386)	17.9**	H<I			
Time on informational pages	464 (333)	362 (387)	537 (312)	537 (312)	451 (359)	451 (359)	287 (303)	471 (334)	423 (334)	363 (387)	363 (387)	498 (325)	5.8*	H<I			
Pages viewed (incl vce pages)	13.3 (8.7)	10.4 (5.3)	20.4 (10.9)	20.4 (10.9)	15.6 (9.9)	15.6 (9.9)	7.7 (3.6)	20.7 (11.5)	17.4 (11.4)	10.6 (5.4)	10.6 (5.4)	20.5 (11.2)	23.3**	H<I			
Informational pages	13.3 (8.7)	10.4 (5.3)	15.1 (6.6)	15.1 (6.6)	12.8 (6.4)	12.8 (6.4)	7.7 (3.6)	13.3 (7.3)	11.9 (6.9)	10.4 (5.3)	10.4 (5.3)	14.1 (7.0)	8.7**	H<I			
Knowledge													NS				
After viewing the DA	7.5 (1.6)	7.1 (2.1)	6.9 (2.0)	6.9 (2.0)	6.9 (2.0)	6.9 (2.0)	6.5 (2.4)	7.5 (1.5)	7.2 (1.8)	7.1 (2.1)	7.1 (2.1)	7.2 (1.8)					

*p<0.05; **p<0.001, NS=not significant M=mean, SD=standard deviation DA=decision aid VCE=values clarification exercise

Table 2 Differences in decision-making, decisional conflict, knowledge and DA use between women who received information only or information plus VCE (subdivided by referral to the VCE, and use of the VCE) (n=197)

	Information plus VCE (VCE+)										Post hoc analysis					
	(N=134)					with referral (n=66)										
	no referral (n=68)					with referral (n=66)										
Information only n=65 VCE-	A	VCE not used n=33 VCE--	B	VCE used n=35 VCE++	C	Total (no referral)	D	VCE not used n=17 VCE--	E	VCE used n=49 VCE++	F	Total (with referral)	G	Total VCE used n=84 VCE++	H	I
Time spent (sec)	464 (333)	362 (387)	669 (360)	520 (401)	663 (407)	566 (416)	520 (401)	287 (303)	663 (407)	566 (416)	363 (387)	566 (416)	665 (386)	17.9**	665 (386)	H<I
Time on informational pages	464 (333)	362 (387)	537 (312)	451 (359)	471 (334)	423 (334)	451 (359)	287 (303)	471 (334)	423 (334)	363 (387)	423 (334)	498 (325)	5.8*	498 (325)	H<I
Pages viewed (incl vce pages)	13.3 (8.7)	10.4 (5.3)	20.4 (10.9)	15.6 (9.9)	20.7 (11.5)	17.4 (11.4)	15.6 (9.9)	7.7 (3.6)	20.7 (11.5)	17.4 (11.4)	10.6 (5.4)	17.4 (11.4)	20.5 (11.2)	23.3**	20.5 (11.2)	H<I
Informational pages	13.3 (8.7)	10.4 (5.3)	15.1 (6.6)	12.8 (6.4)	13.3 (7.3)	11.9 (6.9)	12.8 (6.4)	7.7 (3.6)	13.3 (7.3)	11.9 (6.9)	10.4 (5.3)	11.9 (6.9)	14.1 (7.0)	8.7**	14.1 (7.0)	H<I
Knowledge														NS		
After viewing the DA	7.5 (1.6)	7.1 (2.1)	6.9 (2.0)	6.9 (2.0)	7.5 (1.5)	7.2 (1.8)	6.9 (2.0)	6.5 (2.4)	7.5 (1.5)	7.2 (1.8)	7.1 (2.1)	7.2 (1.8)	7.2 (1.8)		7.2 (1.8)	

* p<0.05; ** p<0.001, NS=not significant M=mean, SD=standard deviation DA=decision aid VCE=values clarification exercise

Discussion

In the above mentioned experiments we assessed the effectiveness of a DA with information only or with additional VCE with regard to knowledge and decisional conflict, and the effect of personality characteristics on DA use and effectiveness. Additionally, we assessed differences in effect between women who did or did not use the VCE. Experiment 1 showed no difference in knowledge or decisional conflict between DAs with or without a VCE. Additional analyses revealed less decisional conflict for women who used the VCE compared to those who did not use the VCE, but it was unlikely that the VCE had caused this difference, since there was no difference in decisional conflict between women who received information plus VCE and used the VCE and women who received information only. In experiment 2 personality characteristics were measured to investigate whether DA- and VCE-use and effectiveness were affected by personality characteristics. Experiment 2 confirmed that there was no association between VCE-use and decisional conflict or knowledge, and showed that information seeking style affected DA use (number of pages viewed), but not VCE-use. Personality traits were to some extent associated with aspects of decisional conflict. In both experiments there was a large knowledge increase of both DAs, indicating that the information in the DA is beneficial with regard to knowledge, especially for women who use the DA more thoroughly, highly conscientious women and women with more monitoring information seeking styles.

Since quality criteria for DAs anticipate on the addition of a VCM to DAs [33], but the results between studies on the effectiveness of VCM vary from beneficial to no (significant) effects [4;7;11-13], we thought it was important to study the effect of our DA plus VCE before implementing it in patient care. However, it seems that not all patients or participants tend to use a VCE when available. In both our experiments there were women who had used the information on the DA, but not the VCE. Although active referral to the VCE increased use of the VCE, independent of personality or information seeking style, still 17 women (15%) who were referred to the VCE did not use it (*experiment 2*). In the condition without referral about half of the women used the VCE in both experiments. A study with patients who were actually facing the decision to undergo FP found even lower percentages of patients (23%) that used their VCE [34;35]. Although VCE-use does not have to take much extra time (in our experiments: ± 5 minutes), it is an extra effort in the already short time patients have to get informed and make a decision, so it should be considered whether active referral is appropriate. The hereby conducted experiments did not show a direct beneficial effect of VCE-use with regard to knowledge or decisional conflict. Therefore, we found no obvious reason to recommend *increasing* VCE-use by actively referring patients to it. Since other VCM were not always beneficial either, quality criteria should perhaps be more cautious regarding VCM recommendation as well [36].

We did find a beneficial effect of both DAs (with or without VCE) on knowledge, since use of the DA lead to a relative knowledge increase of 71-81% compared to baseline (respectively *experiment 2 and 1*), and time spent on the DA was related to knowledge increase after using the DA. It is likely that the increase in knowledge is mostly related to the informational pages.

None of the personality characteristics or information seeking styles were associated with VCE-use; information seeking styles were only associated with DA-use in general, and personality was only associated with decisional conflict. However, effect sizes

were small (<.3). Consistent with the literature, women with more blunting coping styles viewed less pages on the DA website [27;37]. More neurotic women reported to be more uncertain about the decision. However, Case et al (2005) mention that information seeking style does not only depend on personality, but also on the threat and controllability that is experienced, and on the desired effect of the information. I.e., information can be used to do something about a potential threat, or to be reassured that there is no threat [38]. Additionally, anticipated emotions that are imagined with potential outcomes of decision making may affect the decision [26]. It is possible that our healthy participants did not really experience the threat, or a desired emotion, which affected their information seeking style and their decision making process. Also, it is likely that actual patients are sadder than healthy participants, and therefore elaborate more on information [39;40]. However, in the current experiments we were not able to study this properly. It is possible that participants in experiment 1 were more similar to patients because of their emotion induction with sad and anxious emotions.

In these experiments, levels of decisional conflict were relatively high (worse) compared to other studies with patients [12;41-43] and healthy participants [10], but comparable to studies with healthy students as participants [7;44]. Possibly, in contrast to what we would have expected, not actually facing the decision made decision making harder. Moreover, most studies who assessed decisional conflict in patients studied primary treatment decisions, which are different decisions than the decision to undergo FP or not, which is an “extra” decision that has to be made in an emotionally challenging period between diagnosis and start of the oncologic treatment [45;46]. For patients it is often a decision between their chances for survival, the extent of their desire for children and their possibilities for FP (related to personal characteristics)[47]; factors that often exclude some FP options and therefore might facilitate decision making. Likely, healthy students did not take these factors into account which may have increased their decisional conflict scores. Additionally, students are high educated and may therefore approach the decision more analytically which may increase decisional conflict scores. Interestingly, other studies with actual patients [4;13] more often found beneficial effects of VCEs than studies with healthy participants[7;10].

These results have to be interpreted with caution due to some limitations. The DA used in this study was originally designed for patients, who make the decision in consultation with a physician, not directly after viewing the DA, so results of a healthy population making the decision by themselves, directly after viewing the DA may not be completely generalizable to patients that are actually facing this decision. Moreover, it is possible that a DA has more effect on decisional conflict and preparation for decision making sometime after the decision is made[13]. In experiment 1, fewer women than expected used the VCE, which reduced our power. Therefore we added a third condition to the second experiment, in which women were actively referred to the VCE.

Conclusions

The above mentioned experiments indicate that our DA about FP for breast cancer patients seems beneficial with regard to knowledge increase, but that the VCE does not seem to improve knowledge or decisional conflict. Additionally, it is important to understand that personality characteristics and information seeking style may be important factors

in determining the extent to which DAs are used and helpful for women. It is of utmost importance that these findings are assessed in patients as well, since results may be different when actually facing the decision to preserve fertility.

References

- [1] Kassirer JP. Incorporating patients' preferences into medical decisions. *N Engl J Med* 1994 Jun 30;330(26):1895-6.
- [2] Epstein RM, Peters E. Beyond information: exploring patients' preferences. *JAMA* 2009 Jul 8;302(2):195-7.
- [3] Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2011;(10):CD001431.
- [4] O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2009;(3).
- [5] Elwyn G, O'Connor AM, Bennett C, Newcombe RG, Politi M, Durand MA, et al. Assessing the Quality of Decision Support Technologies Using the International Patient Decision Aid Standards instrument (IPDASi). *Plos One* 2009;4(3).
- [6] Feldman-Stewart D, Brundage MD, Van ML. A decision aid for men with early stage prostate cancer: theoretical basis and a test by surrogate patients. *Health expectations : an international journal of public participation in health care and health policy* 2001;4(4):221-34.
- [7] Abhyankar P, Bekker HL, Summers BA, Velikova G. Why values elicitation techniques enable people to make informed decisions about cancer trial participation. *Health Expect* 2011;14 Suppl 1:20-32.
- [8] Llewellyn-Thomas H. Values clarification. In: Elwyn G, Edwards A, editors. *Shared decision making in health care: achieving evidence based patient choice*, 2nd edition. Oxford: Oxford University Press; 2009:123-33.
- [9] Feldman-Stewart D, Brennenstuhl S, Brundage MD, Roques T. An explicit values clarification task: development and validation. *Patient Education and Counseling* 2006;63(3):350-6.
- [10] Sheridan SL, Griffith JM, Behrend L, Gizlice Z, Jianwen C, Pignone MP. Effect of adding a values clarification exercise to a decision aid on heart disease prevention: a randomized trial. *Med Decis Making* 2010;30(4):E28-E39.
- [11] de Vries M, Fagerlin A, Witteman HO, Scherer LD. Combining deliberation and intuition in patient decision support. *Patient Educ Couns* 2013 May;91(2):154-60.
- [12] O'Connor AM, Wells GA, Tugwell P, Laupacis A, Elmslie T, Drake E. The effects of an 'explicit' values clarification exercise in a woman's decision aid regarding postmenopausal hormone therapy. *Health Expectations* 1999;2(1):21-32.
- [13] Feldman-Stewart D, Tong C, Siemens R, Alibhai S, Pickles T, Robinson J, et al. The impact of explicit values clarification exercises in a patient decision aid emerges after the decision is actually made: evidence from a randomized controlled trial. *Med Decis Making* 2012;32(4):616-26.
- [14] Lee SJ, Schover LR, Partridge AH, Patrizio P, Wallace WH, Hagerty K, et al. American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol* 2006;20;24(18):2917-31.
- [15] Hulvat MC, Jeruss JS. Maintaining Fertility in Young Women with Breast Cancer. *Current treatment options in oncology* 2010;10:308-17.
- [16] Garvelink MM, ter Kuile MM, Hilders CGJM, Stiggelbout AM, Louwé LA. [Fertility

- preservation before chemotherapy] Fertiliteitspreservatie voor chemotherapie. *Ned Tijdschr Oncol* 2013;10:97-104.
- [17] Hershberger PE, Finnegan L, Pierce PF, Scoccia B. The decision-making process of young adult women with cancer who considered fertility cryopreservation. *J Obstet Gynecol Neonatal Nurs* 2013;42(1):59-69.
- [18] Garvelink MM, ter Kuile MM, Fischer MJ, Louwe LA, Hilders CG, Kroep JR, et al. Development of a Decision Aid about fertility preservation for women with breast cancer in the Netherlands. *J Psychosom Obstet Gynaecol* 2013;34(4):170-8.
- [19] Iyengar SS, Wells RE, Schwartz B. Doing better but feeling worse. Looking for the “best” job undermines satisfaction. *Psychol Sci* 2006;17(2):143-50.
- [20] Schwartz B, Ward A, Monterosso J, Lyubomirsky S, White K, Lehman DR. Maximizing versus satisficing: happiness is a matter of choice. *J Pers Soc Psychol* 2002;83(5):1178-97.
- [21] Yang ZJ, McComas KA, Gay GK, Leonard JP, Dannenberg AJ, Dillon H. Comparing Decision Making Between Cancer Patients and the General Population: Thoughts, Emotions, or Social Influence? *J Health Commun* 2012.
- [22] Schwarz N, Clore GL. How do I feel about it? Informative functions of affective states. Toronto, Ontario, Canada. 1988.
- [23] Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psychooncology* 2001;10(1):19-28.
- [24] Gorman JR, Malcarne VL, Roesch SC, Madlensky L, Pierce JP. Depressive symptoms among young breast cancer survivors: the importance of reproductive concerns. *Breast Cancer Res Treat* 2010;123(2):477-85.
- [25] Canada AL, Schover LR. The psychosocial impact of interrupted childbearing in long-term female cancer survivors. *Psychooncology* 2012;21(2):134-43.
- [26] Power TE, Swartzman LC, Robinson JW. Cognitive-emotional decision making (CEDM): a framework of patient medical decision making. *Patient Educ Couns* 2011;83(2):163-9.
- [27] Ong LM, Visser MR, van Zuuren FJ, Rietbroek RC, Lammes FB, de Haes JC. Cancer patients’ coping styles and doctor-patient communication. *Psychooncology* 1999;8(2):155-66.
- [28] Flynn KE, Smith MA. Personality and health care decision-making style. *J Gerontol B Psychol Sci Soc Sci* 2007;62(5):261-7.
- [29] O’Connor AM. Validation of A Decisional Conflict Scale. *Medical Decision Making* 1995;15(1):25-30.
- [30] Rottenberg J, Ray RD, Gross JJ. The handbook of emotion elicitation and assessment. Oxford University Press; 2007.
- [31] Miller SM. Monitoring and blunting: validation of a questionnaire to assess styles of information seeking under threat. *J Pers Soc Psychol* 1987;52(2):345-53.
- [32] Denissen JJ, Geenen R, van Aken MA, Gosling SD, Potter J. Development and validation of a Dutch translation of the Big Five Inventory (BFI). *J Pers Assess* 2008;90(2):152-7.
- [33] Elwyn G, O’Connor A, Stacey D, Volk R, Edwards A, Coulter A, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *BMJ*, 2006; 333(7565): 417.

- [34] Peate M, Meiser B, Cheah BC, Saunders C, Butow P, Thewes B, et al. Making hard choices easier: a prospective, multicentre study to assess the efficacy of a fertility-related decision aid in young women with early-stage breast cancer. *Br J Cancer* 2012;106(6):1053-61.
- [35] Peate M, Watts K, Wakefield CE. The 'value' of values clarification in cancer-related decision aids. *Patient Educ Couns* 2013;90(2):281-3.
- [36] Angela Fagerlin, Michael Pignone, Purva Abhyankar, Nananda Col, Deb Feldman-Stewart, Teresa Gavaruzzi, et al. Clarifying values: an updated review. *BMC Med Inform Decis Mak*, 2013;13 (supplement 2): S8.
- [37] Shiloh S, Ben-Sinai R, Keinan G. Effects of controllability predictability and information-seeking style on interest in predictive genetic testing. *Pers Soc Psychol Bull* 1999;25:1187-94.
- [38] Case DO, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *J Med Libr Assoc* 2005;93(3):353-62.
- [39] Bless H., Bohner G., Schwarz N., Strack F. Mood and Persuasion: A Cognitive Response Analysis. *Pers Soc Psychol Bull* 1990;16(2):331-45.
- [40] Holland R.W., De Vries M, Hermsen B., van Knippenberg A. Mood and the Attitude-Behavior Link The Happy Act on Impulse, the Sad Think Twice. *Social Psychological and Personality Science* 2012;3(3):356-64.
- [41] Wong J, D'Alimonte L, Angus J, Paszat L, Metcalfe K, Whelan T, et al. Development of patients' decision aid for older women with stage I breast cancer considering radiotherapy after lumpectomy. *Int J Radiat Oncol Biol Phys* 2012;84(1):30-8.
- [42] O'Connor AM, Tugwell P, Wells GA, Elmslie T, Jolly E, Hollingworth G, et al. Randomized trial of a portable, self-administered decision aid for postmenopausal women considering long-term preventive hormone therapy. *Med Decis Making* 1998;18(3):295-303.
- [43] Col NF, Ngo L, Fortin JM, Goldberg RJ, O'Connor AM. Can computerized decision support help patients make complex treatment decisions? A randomized controlled trial of an individualized menopause decision aid. *Med Decis Making* 2007 Sep;27(5):585-98.
- [44] Rothert ML, Holmes-Rovner M, Rovner D, Kroll J, Breer L, Talarczyk G, et al. An educational intervention as decision support for menopausal women. *Res Nurs Health* 1997;20(5):377-87.
- [45] Lee RJ, Wakefield A, Foy S, Howell SJ, Wardley AM, Armstrong AC. Facilitating reproductive choices: the impact of health services on the experiences of young women with breast cancer. *Psychooncology* 2011;20(10):1044-52.
- [46] Thewes B, Butow P, Girgis A, Pendlebury S. The psychosocial needs of breast cancer survivors; a qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncology* 2004;13(3):177-89.
- [47] Garvelink MM, ter Kuile MM, Bakker RM, Geense WJ, Jenninga E, Louwe LA, et al. Women's experiences with information provision and deciding about fertility preservation in the Netherlands: 'satisfaction in general, but unmet needs'. *Health Expect* 2013.

