Author: Garvelink, Mirjam
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Chapter 8

Summary and General Discussion

Summary

Chapter 2: *Women's experiences with information provision and deciding about fertility preservation in the Netherlands: 'satisfaction in general, but unmet needs'.*

In this qualitative needs assessment, 33 interviews were conducted with patients who had received a counselling consultation and made a decision about fertility preservation (FP) in the past. Women reported being generally satisfied with all aspects of information provision and decision-making about FP, but more in-depth answers brought to light that the information was not always timely, the information was not always correct, communication between hospitals or members of different specialties was poor and women had the feeling that assertiveness was necessary to receive all relevant information. Suggestions were made to develop informational materials (brochures, websites) for patients and checklists for clinicians.

Chapter 3: *Development of a decision aid about fertility preservation for women with breast cancer in the Netherlands.*

This chapter sequentially reported on all stages of the development of a decision aid (DA) about FP, involving patients, clinicians, and healthy women. The DA was developed according to the International Patient Decision Aid Standards (IPDAS) criteria for evaluation of recommended content and development processes for DAs. Content of the DA was determined by a multidisciplinary team of clinicians, researchers, website developers and text writers. The initiative to develop a DA was welcomed by patients and clinicians, and the proposed DA was deemed acceptable. With input from patients and clinicians, some adaptations were made to the draft DA in order to improve understanding, navigation or presentation. The DA was then understandable for both less and more highly educated women, as both groups had significantly improved knowledge about FP after viewing the DA. Results led to a final DA to be used in patient populations with newly diagnosed breast cancer.

Chapter 4: *A Delphi consensus study among patients and clinicians on the procedure of informing young breast cancer patients about Fertility Preservation.*

In this study, patients, clinicians and nurses were gathered in an expert panel (a Delphi panel, after the Greek Oracle) to reach consensus on the use of a DA about FP to inform patients and on the best procedures to implement and use the DA in oncologic practice (when, by whom, and for which patients). All participants thought information provision about FP was important. Agreement was reached that all eligible patients should be provided with general information about FP (irrelevant by whom) soon after diagnosis, and receive more detailed information from a fertility specialist at a later moment. Further, the procedure should be tailored to the individual and the situational context as much as possible. Potential end-users were motivated to use the DA in practice.

Chapter 5: *Values clarification in a decision aid about fertility preservation: does it add to information provision?*

This chapter reports on two experiments with two different samples of healthy participants who were asked to make a hypothetical decision about FP. The first assessed the effect of a DA with and without values clarification exercise (VCE). The second was an expansion of the first, to assess whether personality characteristics and information-seeking styles influenced DA use and effectiveness. Use of the DAs increased knowledge, especially for women who used the DA more thoroughly, highly conscientious women and women with a more monitoring information-seeking style. Information-seeking style affected DA use (high blunters viewed fewer pages) but not VCE use. Personality traits had some effect on aspects of decisional conflict (neurotic women felt more uncertain and less supported in decision-making; conscientious women, on the contrary, felt more certain). There were no indications that (use of) the VCE was beneficial for knowledge or decisional conflict.

Chapter 6: *Psychometric properties of the Reproductive Concerns Scale in three populations of women.*

This chapter describes the psychometric properties of a Dutch version of the Reproductive Concerns Scale in women with breast cancer, women with fertility problems and healthy women. Results showed that the scale was well able to differentiate between different groups of women (known groups construct validity), was related to theoretically related constructs (construct validity), measured reproductive concerns on a coherent scale (reliability) and was stable over a period of two weeks (re-test reliability). All psychometric properties were comparable in breast cancer patients and women with fertility problems, indicating generalizability and justifying its use as outcome measure for research purposes.

Chapter 7: *Additional value of decision aids in complex clinical situations: Effectiveness of a decision aid about Fertility Preservation for breast cancer patients.*

This chapter describes the effects of the DA in addition to brochures, compared to brochures only, on decision-making about FP in newly diagnosed breast cancer patients. Additionally, results were compared with those in women who received usual care (no additional written information). Both informational sources (brochures and DA) led to increased knowledge. There was a trend towards somewhat increased decisional conflict in the DA group when compared to brochures, but decisional conflict seemed even higher in the usual care group. This indicates a beneficial effect of receiving any additional information with regard to knowledge, but increased decisional conflict after using the DA with explicit values clarification exercise.

General discussion

The main purpose of this thesis was to study the needs of breast cancer patients with regard to information provision about fertility preservation (FP), and to assess whether these would be fulfilled by a web-based decision aid (DA) about FP. We have developed a web-based DA with input from various stakeholders, and assessed whether use of the DA and one aspect of the DA (i.e. a values clarification exercise; VCE) would lead to more knowledge and better decision-making outcomes (assessed in healthy women and patients). Additionally we have assessed for which women the DA could be most effective (assessed in healthy women).

Based on the results of the studies in this thesis, as summarized before, there are two important themes that need further discussion: first, the actual value of a DA above and beyond educational brochures in case of FP, and second, the value of values clarification exercises to facilitate decision-making in general. Before these themes are further discussed, some important limitations are discussed, which are important to consider in interpreting the results of this thesis. Subsequently, recommendations are made with regard to further research and clinical practice.

Methodological considerations (chapters 2–7)

In addition to the strengths and limitations that have already been addressed in the separate chapters, there are some important strengths and limitations of the studies in this thesis that we would like to mention here in detail.

Two strengths are the application of different research designs to answer different research questions (qualitative interviews, a Delphi panel, a cross-sectional study and RCTs) and the inclusion of various types of participants (patients who had made a decision about FP in the past, newly diagnosed patients, participants without cancer and clinicians). The application of different research designs allowed us to rigorously study our proposed aims with the most suitable research methods. Qualitative studies are known to be a good design to explore a field of which not much is known yet (ideal for a needs assessment; *chapter 2*), while more quantitative studies are a good design to quantify effects (pilot and validation studies, effect evaluations). The Delphi panel (*chapter 4*), which combined qualitative and quantitative methods, has been proven a good method to reach agreement among different kinds of experts [1;2]. Within quantitative designs we differentiated between retrospective designs (cross-sectional) allowing us to assess predictors for reproductive concerns (*chapter 6*) and prospective designs to evaluate effectiveness of our DA in RCTs (*chapter 5, chapter 7*). The variety of participants is a strength, since it increases the generalizability of results, but also a weakness, since the DA was originally developed for patients; it is therefore possible that results would have been different if newly diagnosed patients had been included in all studies (for example with regard to measures related to decision-making – hypothetical and actual decisions are not the same (*chapter 5*)). Reasons for not only studying needs and effects in newly diagnosed patients were either practical – i.e. sample sizes can be larger with healthy controls or ex-patients than with newly diagnosed patients (*chapters 2–6*) and ex-patients were thought to add more to the development of new materials because of their experience with information provision and deciding about FP (*chapter 2-4*) – or ethical (when patients are not thought to benefit from a study it is unethical to include them; *chapter 5*). In many cases one can include healthy subjects to study specific aspects of interventions in controlled experiments (*chapter 5*), as long as actual effect evaluations are conducted in actual patients for whom the intervention was developed originally (*chapter 7*).

There were some major limitations as well. In the development of the DA about FP, we involved stakeholders as much as possible (*chapter 2–4*). This improved the quality of the information and likely contributed to (future) implementation of the information provision, but it also led us to compromise the research design (in *chapter 7*). Especially in research on information provision for patients, conflicts of interest might exist between researchers and clinicians. Researchers aim to conduct rigorous research, with conclusions about the effectiveness of newly developed information as an endpoint, whereas clinical stakeholders just want to use the available materials to inform their patients as quickly as possible. Therefore, even though for years clinicians have offered only limited verbal information about FP to their patients, it seemed from a clinical point of view ethically unsound to withhold information materials about FP that are considered better than usual care from a subsample of patients (i.e. women randomized to the control arm). Hence, in addition to the DA we developed educational brochures about FP for the control group and broadly distributed them to hospitals throughout the country. The paper brochures and web-based DA contained the same information about FP options and similar information about cancer treatments and their impact on fertility, but the DA additionally contained background information about normal fertility and an explicit values clarification exercise. Further, brochures were linear, but in the DA patients could choose their navigation method and decide for themselves what proportion of the information to read. Although this compromise made clinicians more willing to participate in the trial, from a research perspective it had some disadvantages. For example, by offering both arms information that is thought to be good (brochures) or better (DA), we compromised the power of our study. Effect sizes were expected to be very small, with the consequence that large participant numbers were required to detect an effect. Offering good information to both study arms in *chapter 7* also led to unexpected results. For example, it resulted in the situation that women in both arms had read the brochures. This may have influenced their DA use and it prevented us from specifically studying the efficacy of the DA compared to brochures, but then it also facilitated the implementation of both informational sources (brochures and DA). Luckily, by addition of an observational control group to the RCT consisting of women who received usual care, we were also able to evaluate some effects of both developed information materials.

Lastly, a major limitation – which was a problem in all quantitative studies in which we aimed to include (breast cancer) patients (*chapter 6–7*) – was the difficulty recruiting young women with breast cancer that fulfilled the inclusion criteria for our studies. A majority of newly diagnosed patients had complete families or no desire for children, and the combination of the difficult time during which patients had to be invited, the increasing number of studies involving breast cancer patients and the burden of a cancer diagnosis made recruiters sometimes hesitant to invite patients, or made patients unwilling to participate.

The sense or non-sense of a DA about fertility preservation

Especially in the case of preference-sensitive medical decisions it is important that patients are aware of all treatment options and their benefits and risks, so that patients can form preferences and, together with the clinician, decide what the best treatment option is – i.e. shared decision-making (SDM). DAs have been developed for many such decisions and have been found to be effective with regard to increasing knowledge on the subject and reducing decisional conflict, leading to more realistic expectations with regard to the treatment and a higher percentage of patients who are able to make a decision [3;4]. Hence, for the preference-sensitive decision of whether or not to pursue FP, we also developed a DA.

Results of this thesis show that the web-based DA with VCE about FP was a good means to *inform* patients about FP. Both in actual patients (*chapter 7*) and in healthy participants (*chapter 3, chapter 5*), a medium to large increase in knowledge was found from using the DA. However, other developed informational sources (DA without

VCE; brochures, which contained similar information about FP but less background information; and no VCE) seemed just as good for knowledge increase (*chapter 5, chapter 7*). Moreover, from the addition of a historical control group who received no (written) information besides a counselling consultation, it became clear that in fact any additional information was beneficial with regard to knowledge increase, compared to receiving only a counselling consultation.

The DA was developed not only as an informational source but also as support in decision-making, so we expected that patients who received the DA would be better able to decide about FP than those who only received brochures about FP, since other studies have reported such effects of DAs [4;5]. For example, pooled results of the review by Stacey et al (2012) indicated that in several screenings and treatment decisions, explicit DAs were more likely to achieve informed, values-based decisions than other DAs [4], and that more detailed DAs led to less decisional conflict compared to simpler DAs [4]. Additionally, a previously developed DA about FP (a C5 booklet with information and values clarification exercises) had beneficial effects with regard to decisional conflict and regret (Cohen's d=.52) compared to usual care (a general guide on early breast cancer development not specifically about FP) [5]. When we compared our DA about FP to usual care, our results were similar to those of Peate et al. (2012), but compared to brochures (our original design), decisional conflict slightly *in*creased after use of the DA (*chapter 7*). Moreover, in our study the effects of brochures only and of DA in addition to brochures were equal with regard to value congruence and percentage of women who were able to decide (*chapter 7*), but women who received brochures reported more effective decision-making than women in the DA group (at T1, *chapter 7*). Secondary analyses in a group of patients who received no additional information compared to patients who received either brochures or the DA revealed that both informational sources increased the sense of being supported in decision-making, but that brochures additionally led to more clarity about values.

But why would a DA not work in the case of FP, when it has proven to be the tool of choice in other preference-sensitive decisions [4;6;7]? Explanations might be sought in (1) characteristics of the decision about FP, (2) characteristics of the DA (layout, content, addition of VCEs) or (3) characteristics of the DA users (personality, information-seeking style, literacy). We will discuss these possibilities one by one in more detail.

First, it is possible that a DA has less benefit in the decision of whether or not to pursue FP because this decision is of a different type compared to other treatment decisions for which DAs have been found effective [4]. It might even be questioned to what extent there is a decision to be made in the case of FP. When women have a future desire for children and consider preserving their fertility, the FP option they choose seems merely determined by the extent to which a child is desired in combination with the highest possible success rates (*chapter 1, chapter 7*) and is often dictated by the situation (available time, risk of metastasis) and patient characteristics (age, parity, having a partner or not [8]). In other decisions for which DAs have been found to be effective, the possible treatment options are perhaps less dependent on patient and situational characteristics. Additionally, decision-making (and FP treatment if chosen) has to take place in the short and emotional period between diagnosis of (breast) cancer and start of the oncologic treatment. Since many oncologists emphasize the urgent need for oncologic treatment rather than the option to pursue FP [9], patients may experience (too) much time pressure in decision-making about FP. Hence, women may not always perceive the decision to undergo FP as an actual decision and may therefore not benefit from DAs that "help them decide".

Another factor that may explain why DAs are not always effective may be the design and content of DAs (with VCEs), in that they may suggest a difficult decision to patients (in an implicitly normative way [10]) and thus increase the decisional conflict of users instead of decreasing it. Stiggelbout et al (2008) found a similar result in a study in patients with an abdominal aneurysm; the DA in their study resulted in fewer patients that were able to decide, and different preferences and choices regarding treatment [10;11]. It is possible that the design and the mentioning of all available FP options in our DA is confusing for some patients, since it suggests that they can choose (between all options), which is not always the case. Also, not all patients may need or want all possible information in order to make up their minds. In our population this seems not to be the case, however (*chapter 7*), since a majority of the patients viewed both the DA and brochures.

Besides informational content, our DA consisted of an explicit VCE. In the development of this VCE, important quality criteria and consideration of other research was incorporated to create a theoretically sound tool (*chapter 3*) [12-14]. However, the possible beneficial effect of a VCE in the stressful and short time that is available for decision-making about FP is not clear for every patient [15] (*chapter 7*), nor could it be proven in healthy women (*chapter 5*). In the latter group, use of the VCE led to more values clarity, more decision-making support and more effective decision-making, but only compared to non-use for women who were able to use the VCE (*first experiment, chapter 5*). There was no difference between women who used the VCE and those who did not use it because they were not able to (women who were randomized to a DA with information only). This indicates that in subgroups, the VCE was beneficial. To assess psychological characteristics of these subgroups, a second experiment was conducted with the same two randomization groups (information only versus information plus VCE) in addition to a third condition (information plus VCE with active referral to the VCE). We assessed not only the effectiveness of the DAs, but also the personality characteristics of the respondents. This experiment revealed several personality characteristics that were related to DA use and its effectiveness but was not able to confirm the beneficial effects of using the VCE that we had found before (neither with nor without referral to it), indicating that it might not have been the VCE or DA alone that caused the earlier effects, but possibly personality or characteristics related to women's use of health-related information (*second experiment, chapter 5*).

Third, as already suggested in the previous paragraph, it is possible that DAs are beneficial with regard to decision-making, but not for every patient – hence pleading against the use of a one-size-fits-all approach [16]. Other studies found possible roles for neuroticism, conscientiousness and monitoring and blunting in seeking medical information [17-19]. In healthy participants we have found that women with blunting information-seeking styles viewed fewer informational pages and spent less time on the total DA (*chapter 5*) [18;19]. Additionally, more neurotic women felt less supported and more uncertain in decision-making, whereas conscientious women felt more certain in decision-making (*chapter 5*)[17]. However it is unclear whether these feelings of uncertainty and support are merely traits of these women, or are actually related to use of the DA. Although the effect sizes of the associations with neuroticism were small (r=.18), it could be an indication of a possible role for personality in the effectiveness of a DA, and an interesting starting point for future research. It is also possible that a woman's personality has a greater influence on her decisional conflict than a DA does and thus modifies the effects of the DA on decisional conflict (*chapter 5*) [17;18]. Unfortunately our sample size was too small to stratify by personality (*chapter 7*), or to assess effect modification by personality. Moreover, it is known that especially neurotic women are at increased risk of reacting with feelings of depression to a negative event (such as cancer) [20]. In our RCT with patients (*chapter 7*), patients in the DA group had higher baseline depressive feelings than those in the brochure group (*data not shown*) and felt less certain in decision-making. It is possible that these women were more neurotic and therefore less certain in decision-making, but not due to the DA. Additionally, patients' literacy may have an important role in the effectiveness of DAs. Sub analyses in the review by Stacey et al (2012) found that DAs were mostly effective in low literate patients [4]. Of the patients in *chapter 7,* a majority were high literate (*data not shown*), which may have contributed to the limited beneficial effects of our DA.

The value of values clarification methods to facilitate decision-making in general?

From the studies in this thesis it appeared that the added value of a VCE in the DA about FP was not clear. The literature about many other DAs with values clarification methods (VCM) is also ambivalent with regard to the effectiveness of VCM [3;6;7;21-24]: some conclude VCM are beneficial, others find no beneficial or no significant effects of VCM. Additionally, effectiveness of VCM seems to differ in different study populations (i.e. patient or healthy populations).

A VCE may suggest a deliberative decision-making process, while there is no consensus as to whether or not medical decisions should be made deliberately, by intuition, or both [23;25-27]. In theory, deliberation (with VCM) and analytical reasoning may not always be beneficial for decision-making [23], since deliberation may overshadow important intuitive feelings that are more difficult to formulate but may be just as important in decision-making [23]. Intuition may play a more prominent role in medical decision-making than is accounted for in many DAs with VCE [23]. A combination of deliberation and intuition has been suggested to be beneficial for values clarification [23], possibly with the addition of specific encouragement for patients to become informed and learn about each option before they make a decision (delayed decision-making) to facilitate an unbiased process of preference construction [23]. Additionally, in designing VCM one could target potential stages of processing in decision-making: representation of the options, pre-selection of possible options, integration and evaluation of information about the options, selection of a final option and implementation of the decision (post-choice) [25].

Recently, an entire issue of the journal *BMC Medical Informatics and Decision-Making* was devoted to updating the evidence regarding development of DAs, with attention paid to VCM as well [28;29]. In this volume, some caution was added to the criterion that stated the need for addition of VCM as obliged part of DAs in the previous version of the IPDAS criteria. This criterion was attenuated due to the small number of evaluations of VCM, and heterogeneity of outcome measures and effects of VCM [13;29;30].

The ambivalent effects of the VCE in the different studies in this thesis, in addition to the inconsistent results in the literature, again emphasize that the black box of VCM is still not resolved. We do not know what the effective or ineffective parts of VCM are and how we should best apply these in future DAs, if at all.

Further research

Development and maintenance of DAs requires much time and resources (financial support, intellectual input). To justify these investments, it is important to assess the effectiveness of using DAs. We should not just develop DAs for all preference-sensitive decisions without first knowing whether, when and how they are useful [31]. However, in conducting future studies on the effectiveness of DAs, some important considerations should be taken into account. For example, future studies on the efficacy of DAs should be performed comparing the DA with actual usual care, not comparing good with better, like we did when comparing the DA to educational brochures (*chapter 7*). Therefore, we need to focus on research designs other than regular RCTs. Possible study designs might use a waiting list control group that will receive the intervention later, or a stepped wedge design [32-34]. Unfortunately, the waiting list solution is only possible for decisions in which there is sufficient time to decide, which was not the case in the decision about FP, and stepped wedge was not possible due to the large number of medical centres, clinicians and departments and limited time to complete the study. But Peate et al (2012) compared their DA about FP with usual care in a non-randomized approach, similar to stepped wedge, which seemed to work well [5]. With this study design, the needs of clinical practice are met – since no information is withheld from patients – without compromising the rigour of research. When studies are merely designed as implementation studies, *efficacy* of the materials cannot be studied. However, it is possible to assess *effectiveness* of the information materials and make a start with implementation in the participating medical centres. For further implementation, we might need to engage other parties, for example health insurance companies, to cover the expenses of promoting and distributing the materials. After all, they might also benefit from better informed patients and more shared decision-making (SDM) between patients and clinicians, since it may lead to more efficient and higher quality care [4;35].

If future experiments confirm the role of personality and information-seeking style in DA use, it might be important to stratify patients per personality trait in DA provision. Individual patients may have different reasons for seeking information and different informational needs and preferences [36-40], which additionally may change over time [41;42]. This can be seen in the different information-seeking behaviours of patients and healthy women in using a DA about FP (*chapter 5, chapter 7*) [5;15]. These research findings, opinions of clinicians and psychological (health) theories emphasize the importance of tailoring information to patients (needs) in general [43-46], as well as for FP (*chapter 4-7*). However, more research is needed on how personality effects DA use and effectiveness, and how tailoring could best be done. Additionally, we need to conduct more large-scale studies with healthy participants to identify the exact roles of different personality styles on information-seeking and decision-making.

VCM are considered to be an important component of DAs. However, the best method for values clarification is still not clear. Therefore it is important that we continue to search for the best VCM [30;47]. Since clarification of values occurs within the entire process of decision-making (from the initial diagnosis and mentioning of the treatment options to the moment that an actual decision is made) [48], VCM should not only be part of decision-making tools, but values clarification should be part of the clinical encounter as well. In determining which kind of VCM is best for a decision, VCM should reflect existing decision-making theories [25;30], and experimental studies should be conducted on aspects of VCM both inside and outside the clinical encounter.

The information and VCM in DAs ought to prepare patients for a consultation with a clinician and subsequent shared decision-making (e.g. by informing them and clarifying their values). An overarching purpose of DAs is thus to facilitate SDM between patient and clinician. Since the DA in this study informed patients but did not necessarily improve decision-making processes or outcomes for all patients, future research should focus on additional strategies for implementing SDM, instead of only focusing on the use of DAs as a possible facilitator of SDM. This DA might *facilitate* SDM by informing patients, but actual SDM is still something that takes place in the clinical encounter between patient and clinician.

Clinical implications

We may conclude from our studies that both brochures and the DA about FP seemed useful for clarifying FP options and made patients feel supported in decision-making, thus indicating a role for both as informational sources. Not enough women used the DA and VCE to attach strong conclusions to their effectiveness. However, in the future, brochures might become old-fashioned, and all relevant medical information should (at least “also”) be accessible via the internet in order to reach all patients. Since it is known that many breast cancer patients use the internet to fulfil other information needs (e.g. with regard to their primary treatment) [49;50], it seems a logic location for patient information regarding FP. One can place a large amount of information on the web, which is easy to update, and patients can access it at any time and from anywhere. Hence, despite indications of a slight increase in decisional conflict from the DA compared to the brochures in this thesis, online information will likely be the future for informing patients about FP options, thus justifying implementation of both materials as informational resources [51]. Moreover, since different patients seem to have different information needs and information-seeking styles it is important to offer them a choice between all available information sources, or to tailor the information. However, caution should be adopted in tailoring the information based on clinicians’ *perceptions* of what patients want or need [52], instead of actual *assessment* of these needs.

Unfortunately, availability of (online) DAs is not enough to achieve their routine use [16]. We know from other studies that if no attention is paid to implementation strategies, many (effective) DAs are not used in practice after the research period is over, because clinicians no longer refer to them [53]. Implementation models emphasize the need for thorough assessment of current procedures and how an intervention fits in, including the acceptability of users and situational context [54;55]. Hence, in order to facilitate implementation of the DA and brochures in clinical care, we conducted a pre-implementation study. Aims of this study were to create awareness of the DA, to increase health care professionals' and patients' motivation to use it and to assess the best procedure of implementing it in clinical practice, thereby taking into account barriers and facilitators (*chapter 4*). Involving stakeholders in the development and implementation of an intervention is an important step in the actual implementation of an intervention [56]. To facilitate *national* implementation of the DA and create awareness of the DA throughout the country, we included medical centres in all regions of the Netherlands, many clinicians and many clinical departments in the RCT (*chapter 7*). Additionally, we used an effectiveness design (instead of efficacy) to assess the effect of the DA (*chapter 7*), which facilitates implementation by embedding the intervention (handing out the DA or brochures) in regular clinical practice. Unfortunately, due to the low number of eligible patients that could be included in the trial (*chapter 7*), offering the DA has probably not yet become a routine. Hence, in the long run, time has yet to prove whether our implementation strategies were sufficient to sustain referral to the DA and brochures as informational sources in clinical practice.

(Future) developments in the field of information provision about FP

Breast cancer patients are only one category of cancer patients that might benefit from improved information about FP. This thesis focused on information provision to breast cancer patients only, but information provision has to be improved for other types of cancer as well! Therefore we are already in the process of developing a generic website (www.kankerenkinderwens.nl) in order to adapt the (information on the) DA for breast cancer patients to a broad range of cancers whose treatment compromises fertility, and thereby also to different kinds of patients (men and children in addition to women).

Not only patients, but also clinicians have mentioned that they would like more knowledge and information sources about FP (*chapter 4*) [57]. This is important for them to be able to better support patients in decision-making. In order to inform clinicians, as well as to have patient information available in another format, we are now in the process of developing a generic educational application ("app") about FP for both patients (males, females and children with various types of cancer) and clinicians. This tool can be used in the counselling consultation as well as at home, and is another step towards improving information provision about FP.

With the availability of different informational sources we can tailor the information provision, as much as possible, to individual patients' preferences. By developing information for clinicians as well, we can make sure that all clinicians have the necessary information to be able to inform all their patients about FP, and have materials to hand out for patients.

General conclusion

The main conclusion of this thesis is that improved information provision was deemed necessary and that the DA about FP developed for this end is acceptable to patients, nurses and clinicians and has beneficial effects with regard to knowledge. Although we cannot say much about effectiveness of the DA given our small sample sizes, it seemed that with regard to decision-making, the DA slightly increased decisional conflict. The method of choice to clarify patients' values is still not clear.

In order to form values and preferences and make (shared) decisions in the consultation with the clinician, patients must be informed first. The DA and brochures can therefore best be used as informational source. Since information-seeking needs and effects of DAs might differ for women with different personalities and given personal- and situational characteristics (partner status, age, disease stage), it is important to tailor the information provision as well as the procedure (timing) to patient needs as much as possible. Effects of DA use on the consultation should still be studied, as well as the effectiveness of the VCE in a larger population.

With regard to the procedure of informing patients, it is important that clinicians have sufficient knowledge about FP and include information provision about FP as a standard agenda item in consultations with young women with breast cancer.

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