

**Universität  
Basel**

Fakultät für  
Psychologie



# FERTILITY PRESERVATION IN FEMALE CANCER PATIENTS

PSYCHOLOGICAL IMPACT AND  
INTRODUCTION OF AN ONLINE DECISION AID

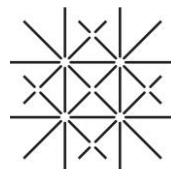
## **Inauguraldissertation**

zur  
Erlangung der Würde  
einer Doktorin der Philosophie  
vorgelegt der  
Fakultät für Psychologie  
der Universität Basel

von

Verena Ehrbar  
aus Basel

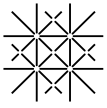
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Psychologie



Genehmigt von der Fakultät für Psychologie  
auf Antrag von

Prof. Dr. phil. Jens Gaab

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Basel, den \_\_\_\_\_

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Prof. Dr. phil. Roselind Lieb



## **Acknowledgments**

I want to address my sincerest gratitude to my supervisor PD Dr. med. Sibil Tschudin. She was available at any time for all of my concerns and supported me in word and deed. With helpful and benevolent advice, her inspiring professional career and her trust in me, she encouraged me in pursuing a scientific career. I am glad having the opportunity to continue working in her team and carry on the research we started together.

A very special thanks goes to Dr. phil. Corinne Urech, who supported me in her professional and kind way. I especially appreciate her support during my speeches, where thanks to her presence, I immediately felt at ease. Knowing her for some years now, she has become a role model in her way of working with patients, with her team, and as a person.

I further thank Prof. Dr. phil. Jens Gaab for his support and helpful advice as PhD supervisor. He provided me with interesting and challenging scientific inputs, from which I have learned a lot.

In terms of the realisation of the online Decision Aid, I want to thank Prof. Dr. med. Christoph Rochlitz, PD Dr. med. Rosanna Zanetti Dällenbach, Dr. med. Rebecca Moffat and Dr. med. Astrid Ahler, who provided the medical content of the Decision Aid. I thank the web-service agency Yoo Applications AG, who helped to create an appealing webpage. I also want to thank all fertility centres and hospitals in Switzerland and Germany for supporting our study. And of course, a very special thanks goes to all study participants who graciously volunteered their time for this study during a sensitive period in their lives.

I also want to thank my team of psychologists at the Women's Hospital Basel for their constant support. A sincere thanks goes to Theresa Tondorf, who provided me with helpful feedback especially in the last phase of writing this thesis.

Furthermore, I would like to thank all my close friends, especially Patrizia Hofer and Ivana Tamburic, for their patience, kindness and believing in me.

Last but certainly not least, I express my gratitude to my beloved partner Tobias Adler. His unconditional support, patience and constant optimism helped me during every phase of my PhD. He always finds the right words to say and with him by my side, everything seems possible.

## **Declaration of Independence**

My cumulative dissertation is based on four manuscripts. I have contributed independently and substantially to this dissertation without any assistance from third parties not indicated. The submitted articles were written in collaboration with the mentioned co-authors. Neither the author, co-authors nor any other persons published the articles elsewhere. I have used only the resources indicated and cited all references.

For the purpose of the cumulative dissertation, the following articles have been submitted for publication in peer-reviewed journals.

### Article 1:

Urech, C., **Ehrbar, V.**, Boivin, J., Mueller, M., Alder, J., Zanetti Daellenbach, R., Rochlitz, C. & Tschudin, S. (2017). *Knowledge about and attitude towards fertility preservation in young female cancer patients: a cross-sectional, binational survey*. Manuscript submitted for publication.

### Article 2:

Mueller, M., Urech, C., Boivin, J., **Ehrbar, V.**, Moffat, R., Zanetti Daellenbach, R., Rochlitz, C. & Tschudin, S. (2017). *Young female cancer patients' decisional conflict about fertility preservation – results of an online survey*. Manuscript submitted for publication.

### Article 3:

**Ehrbar, V.**, Urech, C., Alder, J., Harringer, K., Zanetti Daellenbach, R., Rochlitz, C. & Tschudin, S. (2016). Decision-making about fertility preservation - qualitative data on young cancer patients' attitudes and needs. *Archives of women's mental health*, 19(4), 695-699.

### Article 4:

**Ehrbar, V.**, Urech, C., Rochlitz, C., Zanetti Daellenbach, R., Moffat, R., Stiller, R., Faeh, M., von Wolff, M., Nawroth, F., Dangel, A., Germeyer, A., Findekle, S., & Tschudin, S. (2017). *Fertility preservation in young female cancer patients – development and pilot testing of an online decision aid*. Manuscript submitted for publication.

## Contents

<b>Acknowledgments</b> .....	<b>1</b>
<b>Declaration of Independence</b> .....	<b>2</b>
<b>Abstract</b> .....	<b>4</b>
<b>Background</b> .....	<b>6</b>
The decision to make .....	6
Psychological impact.....	7
Lack of knowledge .....	7
Decisional conflict.....	8
Comprehensive support .....	8
<b>Overview of the Research Project</b> .....	<b>10</b>
Online Survey .....	10
Focus Groups .....	11
Decision Aid .....	11
<b>Summary of Results</b> .....	<b>12</b>
Article 1 .....	12
Article 2 .....	12
Article 3 .....	13
Article 4 .....	13
<b>Discussion</b> .....	<b>14</b>
Knowledge.....	14
Decisional Conflict.....	15
Limitations.....	16
Clinical implications.....	17
Future Directions .....	17
<i>Expansion of the content</i> .....	17
<i>Translations</i> .....	17
<i>Men and FP</i> .....	18
Conclusion .....	18
<b>Personal efforts</b> .....	<b>19</b>
<b>References</b> .....	<b>20</b>

## Abstract

The aim of the research project presented with this cumulative dissertation was to get a deeper insight into psychological aspects of young female cancer patients concerning fertility preservation (FP) and the development of an online decision aid (DA). A mixed-method approach was applied to the first part of the research project with an online survey and focus groups. Objectives were to assess the significance of fertility and fertility-related knowledge in these patients, their attitude towards FP, their decisional conflict and helpful support tools.

Article 1 “*Knowledge about and attitude towards fertility preservation in young female cancer patients: a cross-sectional, binational survey*” and article 2 “*Young female cancer patients’ decisional conflict about fertility preservation – results of an online survey*” comprise results of the online survey about fertility issues, which was completed by 155 former female cancer patients from German and English speaking countries. Summarizing the findings, knowledge about FP was limited but positive attitudes towards FP significantly outweighed negative attitudes. Decisional conflict was considerable, especially with regard to missing information and support. However, decisional conflict was significantly lower in patients who discussed the risk of infertility with a health professional, who underwent a FP procedure and in patients who had a university level education.

To enrich these quantitative data, four focus groups with 12 female cancer survivors were conducted, which are described in article 3 “*Decision-making about fertility preservation – qualitative data on young cancer patients’ attitudes and needs*”. Results confirmed previously gained data. The significance of fertility was high and attitude towards FP positive. Religious and ethical reservations were not negligible. Patients wished for more support and specific tools would be appreciated. These results lead to the conclusion that greater emphasis should be placed on counselling opportunities as well as on the provision of adequate information and supporting material. It is hypothesized that this may be a possible strategy to lower decisional conflict and improve fertility-related knowledge.

Therefore, as second part of the research project, we developed an online DA for female cancer patients concerning their decision whether to opt for FP or not. Article 4 “*Fertility preservation in young female cancer patients – development and pilot testing of an online decision-aid*” describes the development of the DA and the pilot study, which was conducted to get first data on the effectiveness and acceptability of the DA. The study was a prospective consecutive study with 40 female cancer patients. Data showed that the DA was considered helpful for decision-making and recommendable by nearly all participants. Knowledge about FP was high regarding FP techniques women went for. Mean decisional conflict was moderate

whereas 20% showed scores above the threshold for high decisional conflict. A current randomized controlled trial is ongoing to confirm these data.

Our research project has demonstrated that distress and burden due to the decision making process is considerable. Therefore, a deeper insight into psychological aspects of patients who have to make their decisions on FP is an important goal for research aiming to provide support in this challenging situation. In order to allow patients to make an informed choice, referring patients to fertility counselling is inevitable. The here presented DA enriches existing health service offers for young cancer patients by providing additional support for patients as well as professionals.

## **Background**

When an individual is confronted with a cancer diagnosis, the first priority of patients and their caretakers is survival. Due to recent advances in cancer therapy, the cure rates for certain malignancies may exceed 90% (Jemal et al., 2004). There is an increased number of long term cancer survivors and quality of life is of growing importance (Forman, Anders, & Behera, 2010; Maltaris et al., 2007). Unfortunately, as a consequence of cancer treatment, fertility may be impaired due to gonadotoxic effects of chemo- and radiotherapy (Loren et al., 2013; Maltaris et al., 2007). There are nowadays several options available to preserve fertility to women and men affected by cancer and it is of utmost importance to discuss these options with all patients before the onset of cancer treatment (Lee et al., 2006; Tschudin & Bitzer, 2009). As cancer treatment has generally to be started as soon as possible, the decision whether to undergo any fertility preservation (FP) procedure needs to be taken in a very short time frame.

### *The decision to make*

FP techniques for women have advanced very fast over the last few years. Some of the techniques are well established like for example the hormonal stimulation of the ovaries with cryopreservation of oocytes or embryos. This technique needs usually around 2 to 3 weeks before cancer treatment can be started. Other techniques like surgical removal of ovarian tissue are more invasive and are less well-established. The advantages of the latter technique is, that it can be performed without delaying the start of cancer treatment (Hudson, Stanley, Nahata, Bowman-Curci, & Quinn, 2017). Another option without removal of oocytes or ovarian tissue is ovarian protection with hormonal injections (GnRH agonists). The effectivity of this method is controversially discussed (von Wolff et al., 2011).

In addition to the medical facts, women must be informed about the costs and follow-up costs, as in most of the cases, an in vitro fertilization (IVF) is needed. In Switzerland as well as in many other countries, FP is not covered by health insurance. In every country, the legislation strictly regulates handling of oocytes and ovarian tissue.

Besides the medical and practical aspects of FP, many young cancer patients may feel unprepared to take a major decision about their future fertility and family planning.



### ***Psychological impact***

Given the life-threatening nature of cancer, an individual's capacity to process information becomes limited and for some individuals, life issues apart from overcoming cancer grow out of focus when confronted with this diagnosis (Loi et al., 2010). Taking a decision about FP may feel like an additional burden. Nevertheless, fertility is associated with new life (Tschudin & Bitzer, 2009) and thinking about a future parenthood may provide hope. It is an ethically and emotionally complex field, in which various meaningful issues have to be addressed. The situation, with which patients, their families and the caretakers are confronted, is especially challenging and its psychological impact is considerable (Tschudin & Bitzer, 2009).

To date a growing body of literature on psychological aspects concerning FP exists. Most data is derived from surveys as well as qualitative and exploratory studies published during the last decade and discussed in two reviews (Peate, Meiser, Hickey, & Friedlander, 2009; Tschudin & Bitzer, 2009). Patients report that fertility is an important issue to them, that they are concerned about their future fertility and want to preserve it (Dunn & Steginga, 2000; Partridge et al., 2004; Schover, Rybicki, Martin, & Bringelsen, 1999; Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004). Giving patients the opportunity to preserve fertility may improve quality of life (Howard-Anderson, Ganz, Bower, & Stanton, 2012; Tschudin & Bitzer, 2009), and whilst the possibility to have biological children is retained (Howard-Anderson et al., 2012).

### ***Lack of knowledge***

Patients as well as medical caretakers have substantial knowledge and information deficits (Goodwin & Oosterhuis, 2007; Quinn, Vadaparampil, Bell-Ellison, Gwede, & Albrecht, 2008; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). Due to this lack of knowledge, physicians hesitate to address FP (Li et al., 2015; Quinn et al., 2007) and as a consequence do not refer patients to fertility specialists.

The percentage of patients that recall having received counselling about fertility issues varies enormously between studies and ranges from 34% to 72% (Duffy, Allen, & Clark, 2005; Partridge et al., 2004; Schover et al., 2002; Schover et al., 1999; Thewes et al., 2005; Zebrack et al., 2004). Various studies have shown that it is often the patient herself, who initiated the discussion about fertility, rather than the oncologist or other medical caretakers (Kim et al., 2013; Yee, 2015). Furthermore, cancer patients reported not feeling involved enough in the

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decision-making process and that they considered themselves inadequately informed about their options of FP (Crawshaw, Glaser, Hale, & Sloper, 2009; Wilkes, Coulson, Crosland, Rubin, & Stewart, 2010).

### ***Decisional conflict***

In addition, many studies have shown that patients have a considerable decisional conflict regarding FP (Bastings et al., 2014; Mersereau et al., 2013; Peate et al., 2011b). Decisional conflict is defined as a state of uncertainty about a course of action to take (O'Connor, 1993) “when choice among competing options involves risk, loss, regret, or challenge to personal life values” (LeBlanc, Kenny, O'Connor, & Legare, 2009, p. 61). Factors that may increase decisional conflict in young cancer patients are: uncertainty of the impact of cancer treatment on future fertility, safety concerns, time constraints, and financial considerations (Mersereau et al., 2013). However, previous studies revealed, that if patients have sufficient knowledge and are aware of their personal values, it is more likely that they can make an informed choice (Flink, Sheeder, & Kondapalli, 2017; Marteau & Dormandy, 2001; Tschudin et al., 2011).

### ***Comprehensive support***

A study by Wilkes et al. (2010) including female and male cancer patients confronted with decision making about FP showed that the quality of information and the support that was offered positively correlated with both the experience of counselling and the decision-making process in general. Thereby, information material needs to be tailored to the patient's individual situation, i.e. age, diagnosis and life situation (Wilkes et al., 2010). Moreover, when appropriately informed about FP, cancer patients are more satisfied with their counselling experience (Balthazar et al., 2012) and reported less regrets about their decision (Crawshaw et al., 2009). However, the availability of helpful information is still low and patients wish for more support (Garvelink et al., 2015). One possibility to improve offers of support may be by providing decision aids (DAs).

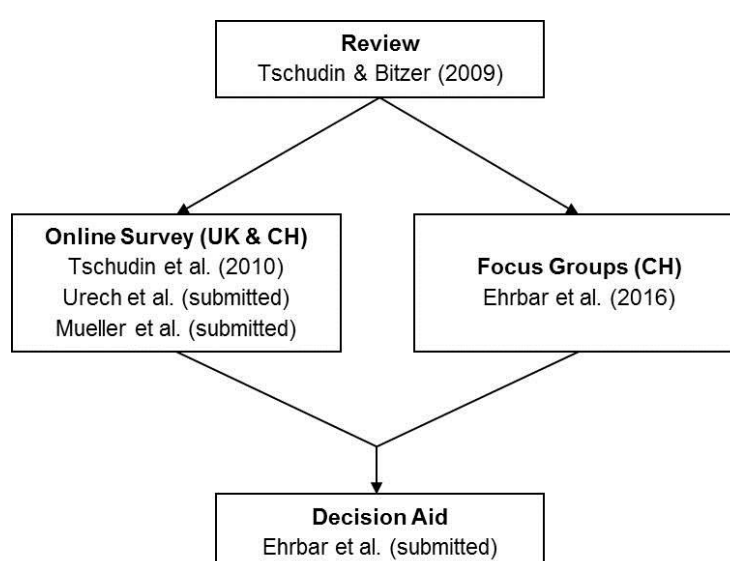
DAs consist of educational materials and/or tools designed to support patients in health care decisions. They help patients understanding potential risks and benefits of different options as well as to embrace their personal values in the decision-making process (Stacey et al., 2014). A Cochrane review including 115 studies about DAs showed high-quality evidence that DAs compared to usual care are able to increase patients' knowledge and decrease their decisional

conflict as well as to include patients more active in the decision-making process (Stacey et al., 2014). DAs are very helpful instruments, especially when time for decision-making is limited (Nicholas, Butow, Tesson, & Boyle, 2016). Particularly in the cancer context, DAs have shown to be successful in encouraging patients to involve them in decision-making (Nicholas et al., 2016; O'Brien et al., 2009).

Previous research showed that having a DA at disposition was or would in fact be highly appreciated by young cancer patients (Garvelink et al., 2013). There are a small number of research groups who have been developing and evaluating DAs for cancer patients regarding FP. An Australian working group developed and evaluated a DA booklet for breast cancer patients (Peate et al., 2011a) and a Dutch research group did an online DA for breast cancer patients (Garvelink et al., 2013). Both DAs were able to show effects in improving fertility-related knowledge (Garvelink, Ter Kuile, Louwe, Hilders, & Stiggelbout, 2016), reducing decisional conflict, and increasing satisfaction with the decision (Peate et al., 2012). Currently, there is another English DA under development (Jones et al., 2017). We are the first research group, who is developing and evaluating a German DA in this context.

## Overview of the Research Project

Considering the still limited knowledge on psychological aspects in the topic of cancer and FP, the review by Tschudin and Bitzer (2009) was the starting point of our research project. The overall objective of the research project was to get a deeper insight into the significance of fertility for female cancer patients, their fertility-related knowledge, their attitude towards FP as well as their decisional conflict regarding the many options of FP and specific needs or helpfulness of various sources of support. In a first step, an online survey and focus groups to receive information about the psychological impact on fertility issues were conducted. Based on these results, we developed and evaluated a web-based DA for female cancer patients regarding their decision on FP (Fig. 1).



*Figure 1: Overview of the research project including publications / manuscripts*

### ***Online Survey***

The online survey was conducted with 155 former female cancer patients. The questionnaire was specifically conducted for this study and in collaboration with the Cardiff University UK. Thus, as participants from the UK as well as from Switzerland and Germany completed the questionnaire, we have not only different cultural backgrounds but also experiences with different health care systems. The online survey and its results are described in article 1 and 2.

### ***Focus Groups***

In order to enrich the quantitative data gained with the online survey, we conducted four focus groups. Focus groups are one specific and well-established method of qualitative research and allow to describe, interpret and understand patients' experiences and perspectives, which might not be accessible in quantitative research methods (Liamputtong, 2011; Packer-Muti, 2010). These focus groups are targeted at providing in-depth information on the experience and needs with regard to FP of the participants, as well as on their wish of support regarding decision-making. This qualitative study is described in article 3.

### ***Decision Aid***

Based on the results of the quantitative and qualitative part of our research project as well as the current state of research, we developed and evaluated a web-based DA for women with cancer who needed to decide whether to opt for FP or not. An online format of the DA represents an ideal way of addressing young cancer patients, as they are familiar with the internet and consider it as their main source of information (Fleisher, Bass, Ruzek, & McKeown-Conn, 2002; Meneses, McNees, Azuero, & Jukkala, 2010). Also, it is known, that the internet is frequently used by people to gain information about health-related topics including fertility (Bass, 2003).

We first conducted a prospective, consecutive intervention study with a control group, who received standard fertility counselling, followed and compared with an intervention group, who, in addition to fertility counselling, got access to the online DA. The evaluation of this pilot study and the development of the DA are described in article 4. Following to this pilot study, we started a randomized controlled trial, which is still on going.

## Summary of Results

The following pages contain a brief overview of the main results of each article. Article 1, 2 and 4 are submitted to peer-reviewed journals, whereas Article 3 was published. All articles are listed in the appendix, where further information on methods and detailed descriptions of the results may be found.

### *Article 1*

*“Knowledge about and attitude towards fertility preservation in young female cancer patients: a cross-sectional, binational survey”* (Urech et al., submitted)

This article describes results from the online survey with a sample of 155 former female cancer patients from German and English speaking countries. Results have shown that knowledge about FP was limited. Positive attitudes towards FP significantly outweighed negative attitudes. Knowledge and attitudes did not differ according to language and cultural background, but partly depending on whether they underwent FP procedures or not.

### *Article 2*

*“Young female cancer patients’ decisional conflict about fertility preservation – results of an online survey”* (Mueller et al., submitted)

This article also consists of results of the online survey and aimed at assessing decisional conflict in young female cancer patients concerning FP as well as identifying demographic, fertility- and FP-related factors, which may affect decisional conflict. Another aim was assessing the helpfulness of various decision-supports. Participants showed a considerable decisional conflict, especially with regard to missing information and support. Decisional conflict was significantly lower in patients who discussed the risk of infertility with a health professional, who underwent a FP procedure and in patients who had university education. A longer time interval since cancer diagnosis was associated with higher decisional conflict. The most helpful decision-support tools were specialized websites and leaflets.

### ***Article 3***

*“Decision-making about fertility preservation – qualitative data on young cancer patients’ attitudes and needs”* (Ehrbar et al., 2016)

This article provided qualitative data on psychological aspects of FP and the aim of the study was to get deeper insight into the significance of fertility in cancer patients, their attitude towards FP, decisional conflict, and patient’s needs in the decision-making process. Focus groups with 12 female cancer survivors revealed that the significance of fertility was high and attitude towards FP positive. Religious and ethical reservations were not negligible. Standardized decision aids were considered helpful. More support is highly in demand and specific tools would be beneficial.

### ***Article 4***

*“Fertility preservation in young female cancer patients – development and pilot testing of an online decision-aid”* (Ehrbar et al., submitted)

Aside from describing the process of development and the content of an online DA in German, the objective of the presented article was to pilot test users’ satisfaction with the DA and its effect on knowledge about FP and on decisional conflict. In this prospective consecutive study a control group (n=20, fertility counselling) was followed by and compared with an intervention group (n=20, counselling and additional use of the DA, developed by an interdisciplinary team) of recently diagnosed female cancer patients. Nearly all participants, who applied the DA, considered it helpful for decision-making and recommendable. Knowledge about FP was high with regard to FP techniques women went for. Decisional conflict was moderate and only in 20% the score was above the threshold for high decisional conflict. There was no difference between the control and intervention group for knowledge and decisional conflict.

## **Discussion**

The aim of our research project was to get insights into the significance of fertility in young female cancer patients, their attitude towards FP, their fertility-related knowledge and decisional conflict as well as the support they demand.

Results from the online survey and focus groups showed that fertility is an important issue for these patients and attitude towards FP was predominantly positive. However, knowledge about FP was low and the decision on FP was considered to be very difficult. Patients wished for more standardized support, such as DAs. FP is an important issue and this awareness needs to be increased not only in patients but also in medical caretakers.

Data from the prospective consecutive pilot study with the online DA as additional source of support after counselling showed that knowledge was high with regard to the three most used FP techniques in this sample and all participants felt confident in their fertility-related knowledge. Mean overall decisional conflict was moderate, whereas 20% of the sample showed a high decisional conflict. The DA was perceived as helpful support and most of the participants would recommend it to others.

### ***Knowledge***

Many studies showed that patients' knowledge about cancer and its impact on fertility before counselling was poor (Balthazar, Fritz, & Mersereau, 2011; Goodwin & Oosterhuis, 2007; Peate et al., 2011b; Quinn et al., 2008), which is in line with results of our online survey (Urech et al., submitted). In addition, a recent study by Balthazar et al. (2012) showed that fertility-related knowledge remains limited even after FP counselling. Knowledge scores of these participants were low with an average of 50% correct answers. In contrast to that, results of our pilot study (Ehrbar et al., submitted) showed that knowledge after counselling about FP was high with regard to FP techniques women went for. However, our pilot study was not able to show significant differences of knowledge scores between the two groups, which was most probably due to the small sample size. Our ongoing randomized controlled trial will show if we can demonstrate a favourable effect of the DA compared to counselling only.

Many studies stated that patients should understand the impact of their cancer diagnosis and its treatment on fertility (Balthazar et al., 2011; Goodwin & Oosterhuis, 2007; Peate et al., 2011b; Quinn et al., 2008). They need to know if there are options available in order to make



adequate decisions about their future fertility. Some predictors have been identified which are more likely to improve knowledge after counselling, such as higher education, additional contact with a fertility specialist, discussing FP options with someone else and using educational material such as specific websites and/or DAs (Balthazar et al., 2012). This shows the high need of comprehensive information provision in terms of referring patients to fertility counselling and providing them additional support with educational material like it is the case in DAs.

However, it has to be taken into account that having more knowledge is not always in favour of the patient. Stiggelbout et al. (2008) showed that patients with more knowledge reported more insecurity and less faith in the doctors opinion (Stiggelbout et al., 2008). Individuals may be overwhelmed or confused with too much information. Based on this knowledge, the amount of information provision should whenever possible be tailored as individual as possible to the characteristics of the recipient. Further studies, our ongoing trial included, need to focus more on the influence of knowledge on decisional conflict as well as satisfaction with the decision.

### ***Decisional Conflict***

Having a closer look at the results of our pilot study (Ehrbar et al., submitted), with a specific focus on the outcomes regarding decisional conflict, the data reveals that the control group showed a slightly lower decisional conflict as the intervention group, but not significant. This is contrary to what we expected with our hypothesis, but similar to the results of a study recently published by Garvelink et al. (2016). These as well as other authors discussed various explanations of this on a first sight, contradictory result, which may also imply explanations for the results in our study.

First, the fact that the decision needs to be taken in a very short and emotional challenging time, an increase in decisional conflict may be expected to occur naturally. An explicit confrontation of this challenging decision through a DA may increase this decisional conflict even more (Nelson, Han, Fagerlin, Stefanek, & Ubel, 2007). Second, when time to take a decision is as limited as it is the case of FP, many participants may already have a strong preference in mind or may even already have taken the decision before using the DA (Nelson et al., 2007). Using the DA afterwards may confront patients with more/new information, which may lead to more uncertainty and thus a higher decisional conflict (Garvelink et al., 2016). As decisional conflict often represents a primary objective of effectiveness studies about DAs,

some studies consequently may report limited effects because of this natural increase of decisional conflict (Goel, Sawka, Thiel, Gort, & O'Connor, 2001).

Important to keep in mind is that a slight increase in decisional conflict is not disadvantageous (Knops et al., 2013; Nelson et al., 2007), especially when decisional conflict is not above the threshold for a high decisional conflict, which was not the case in our sample. Nelson et al. (2007) suggests that a higher decisional conflict indicates that women are strongly involved in the decision. A certain amount of uncertainty needs to be expected and should not be interpreted as unfavourable (Nelson et al., 2007).

### *Limitations*

Some limitations need to be considered and taken into account for further research. The presented results are specific to this sample and cannot be generalized to all women with cancer. Not all cancer types were covered. As in many other studies, most of the participants were breast cancer patients. The majority of the participants were highly educated, which is a common bias in studies. Medical data of participants of the online survey were self-reported and not confirmed by physicians. The study design of the online survey and focus groups were retrospective, which means that participants might not have remembered all details and a recall bias needs to be taken into account. With regard to the online survey, it has to be considered that the composition of an online sample is arbitrary and prone to bias. On the contrary, due to the online recruitment we might have addressed the target group of internet users among female cancer patients, who may demand and potentially benefit from an online support tool. With regard to the evaluation of the DA, the pilot study sample is small and interpretations of these results need to be treated with caution. The presented data was obtained immediately after FP counselling and only further analyses at later time points (T2 and T3) will provide insight in potential score changes of the decisional conflict scale over time between the two groups. Neither in the pilot study nor in the ongoing trial, did we collect baseline data before counselling. Our objective was to assess the effectiveness of the DA as an additional support compared to counselling alone. Therefore, an assessment before counselling was not needed methodologically. Furthermore, asking patients to complete an additional questionnaire in the short time slot after diagnosis and before counselling was practically seen as difficult to organise as well as ethically questionable.

### ***Clinical implications***

The aim of the project is to enrich existing health service offers for young cancer patients in German speaking areas by means of information provision and support tools concerning FP. Websites such as *www.fertiprotekt.de* already exist, which provide helpful information about FP and cancer. However, with making our DA available to all affected cancer patients, we could supply patients and professionals with an additional and more comprehensive source of decision support. Valid information about FP is still difficult to acquire (Hershberger, Finnegan, Altfeld, Lake, & Hirshfeld-Cytron, 2013) and affected patients desire more guidelines or DAs where all information are gathered together (Ehrbar et al., 2016). DAs may be seen as additional material to use in the counselling session (Garvelink et al., 2016) as well as after counselling, retrievable for the patient at any time and place.

However, referral to a fertility specialist is of utmost importance (Kim et al., 2013). A recent study reported that without special training regarding FP, only 6.7% of participating physicians indicated to have initiated a discussion about FP in cancer patients. After receiving the appropriate training, the number of physicians who mentioned FP increased significantly to 46% (Li et al., 2015). Therefore, education for physicians is highly needed in order to provide all cancer patients with information on FP (Anderson & Davies, 2016).

### ***Future Directions***

Due to positive and encouraging feedback on our DA by study participants and professionals, we are planning to extend several parts of the DA as soon as the study is completed. Some of these ideas are presented here:

#### ***Expansion of the content***

An advantage in having developed a web-based DA is that modifications are very easily made. Hence, we aim at expanding the content with more specific information about other cancer types, i.e. leukaemia. Furthermore, many patients appreciate websites that incorporate patient stories (Hershberger et al., 2013), therefore it would be valuable to add personal experiences of other cancer patients to our DA.

#### ***Translations***

Switzerland is a multilingual country, thus a translation of the existing DA into other official languages is mandatory. At the same time, this enables us to offer the DA to a larger number

of affected patients, not only in Switzerland and Germany, but also in countries with the same languages.

### *Men and FP*

To date male cancer patients have been neglected with regard to similar offers, whereas the few existing studies on men confirm that they are confronted with similar challenges in this critical situation (Crawshaw et al., 2009; Wilkes et al., 2010). We are planning a study about FP in male cancer patients in order to fill this gap. By means of a mixed-methods approach we want to explore comprehensively and extensively men's experiences in the given context and thus get a holistic image of men's needs, when confronted with a cancer diagnosis and having to make choices with regard to FP. This will provide us with the necessary knowledge and information to develop an online tool for men.

### *Conclusion*

Individuals who are confronted with a recent cancer diagnosis and the necessity to decide whether or not to opt for FP face a challenging situation in their lives and adequate support is of absolutely necessary. With the data from our research project we were able to demonstrate that the distress and burden due to the decision making process is considerable. Referring patients to fertility counselling is inevitable and additional support tools are highly appreciated. In order to support patients in their decision-making process, we developed an online DA for female cancer patients concerning FP. First data of the pilot study showed a high acceptability of the DA by patients. Efforts to optimise decision-making in this emotionally difficult and challenging situation after a cancer diagnosis can be considered as a contribution to control and minimise devastating long term effects of cancer. Thus, the here presented DA may provide additional support for patients as well as professionals and enrich existing health service offers for young cancer patients.

**Personal efforts**

I started my work as a doctoral student with the development of the online DA. Various fertility specialists, oncologists, gynaecologists, and psychologists supported me developing the content of the DA. An experienced web-service agency helped to establish the tool together with their technical and user-centred expertise. During the development process, I was the leading project coordinator and with the help of all involved professionals, we finally were able to launch the online DA 1.5 years later.

During the development process, recruitment of the control group already started and the most important task at this time was to establish contacts with fertility centres/hospitals. I visited these places regularly to provide them with information and study material and overall to provide best preconditions for the subsequent patient recruitment.

At the same time, I was also substantially involved in the data management of the previously conducted online survey and focus groups and in writing the manuscripts for publication.

Furthermore, I often had the opportunity to present our research data at various national and international congresses (i.e. IPOS, ESHRE or ISPOG), where positive responses and keen interest were shown by other researchers. Within building a professional network, it was a personal highlight to meet Dr. Michelle Peate, whose work was a great inspiration for our DA. Other interesting exchanges with notable researchers in the field of FP and DA have enriched my knowledge and experience, which I will hopefully be able to use in my future career as a researcher.

## References

- Anderson, R. A., & Davies, M. C. (2016). Preserving fertility in girls and young women with cancer. *BMJ*, *355*, i6145. doi: 10.1136/bmj.i6145
- Balthazar, U., Deal, A. M., Fritz, M. A., Kondapalli, L. A., Kim, J. Y., & Mersereau, J. E. (2012). The current fertility preservation consultation model: are we adequately informing cancer patients of their options? *Hum Reprod*, *27*(8), 2413-2419.
- Balthazar, U., Fritz, M. A., & Mersereau, J. E. (2011). Fertility preservation: a pilot study to assess previsit patient knowledge quantitatively. *Fertil Steril*, *95*(6), 1913-1916. doi: 10.1016/j.fertnstert.2011.02.016
- Bass, S. (2003). How will Internet use affect the patient? A review of computer network and closed Internet-based system studies and the implications in understanding how the use of the Internet affects patient. *J Health Psychol*, *8*(1), 25-38.
- Bastings, L., Baysal, O., Beerendonk, C. C., IntHout, J., Traas, M. A., Verhaak, C. M., . . . Nelen, W. L. (2014). Deciding about fertility preservation after specialist counselling. *Hum Reprod*, *29*(8), 1721-1729. doi: 10.1093/humrep/deu136
- Crawshaw, M. A., Glaser, A. W., Hale, J. P., & Sloper, P. (2009). Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years. *Eur J Cancer Care (Engl)*, *18*(4), 381-390. doi: 10.1111/j.1365-2354.2008.01003.x
- Duffy, C. M., Allen, S. M., & Clark, M. A. (2005). Discussions regarding reproductive health for young women with breast cancer undergoing chemotherapy. *J Clin Oncol*, *23*(4), 766-773. doi: 10.1200/JCO.2005.01.134
- Dunn, J., & Steginga, S. K. (2000). Young women's experience of breast cancer: defining young and identifying concerns. *Psychooncology*, *9*(2), 137-146.
- Ehrbar, V., Urech, C., Alder, J., Harringer, K., Zanetti Dallenbach, R., Rochlitz, C., & Tschudin, S. (2016). Decision-making about fertility preservation-qualitative data on young cancer patients' attitudes and needs. *Arch Womens Ment Health*, *19*(4), 695-699. doi: 10.1007/s00737-016-0604-x
- Fleisher, L., Bass, S., Ruzek, S. B., & McKeown-Conn, N. (2002). Relationships among Internet health information use, patient behavior and self efficacy in newly diagnosed cancer patients who contact the National Cancer Institute's NCI Atlantic Region Cancer Information Service (CIS). *Proc AMIA Symp*, 260-264.
- Flink, D. M., Sheeder, J., & Kondapalli, L. A. (2017). A Review of the Oncology Patient's Challenges for Utilizing Fertility Preservation Services. *J Adolesc Young Adult Oncol*, *6*(1), 31-44. doi: 10.1089/jayao.2015.0065
- Forman, E. J., Anders, C. K., & Behera, M. A. (2010). A nationwide survey of oncologists regarding treatment-related infertility and fertility preservation in female cancer patients. *Fertil Steril*, *94*(5), 1652-1656. doi: 10.1016/j.fertnstert.2009.10.008
- Garvelink, M. M., ter Kuile, M. M., Bakker, R. M., Geense, W. J., Jennings, E., Louwe, L. A., . . . Stiggelbout, A. M. (2015). Women's experiences with information provision and deciding about fertility preservation in the Netherlands: 'satisfaction in general, but unmet needs'. *Health Expect*, *18*(5), 956-968. doi: 10.1111/hex.12068
- Garvelink, M. M., ter Kuile, M. M., Fischer, M. J., Louwe, L. A., Hilders, C. G., Kroep, J. R., & Stiggelbout, A. M. (2013). Development of a Decision Aid about fertility preservation for women with breast cancer in The Netherlands. *J Psychosom Obstet Gynaecol*, *34*(4), 170-178. doi: 10.3109/0167482X.2013.851663

- Garvelink, M. M., Ter Kuile, M. M., Louwe, L. A., Hilders, C. G., & Stiggebout, A. M. (2016). Feasibility and effects of a decision aid about fertility preservation. *Hum Fertil (Camb)*, 1-9. doi: 10.1080/14647273.2016.1254821
- Goel, V., Sawka, C. A., Thiel, E. C., Gort, E. H., & O'Connor, A. M. (2001). Randomized trial of a patient decision aid for choice of surgical treatment for breast cancer. *Med Decis Making*, 21(1), 1-6. doi: 10.1177/0272989X0102100101
- Goodwin, T., & Oosterhuis, B. E. (2007). Survivors of childhood cancer. *N Engl J Med*, 356(2), 191-192; author reply 193-194. doi: 10.1056/NEJMc063105
- Hershberger, P. E., Finnegan, L., Altfeld, S., Lake, S., & Hirshfeld-Cytron, J. (2013). Toward theoretical understanding of the fertility preservation decision-making process: examining information processing among young women with cancer. *Res Theory Nurs Pract*, 27(4), 257-275.
- Howard-Anderson, J., Ganz, P. A., Bower, J. E., & Stanton, A. L. (2012). Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: a systematic review. *J Natl Cancer Inst*, 104(5), 386-405.
- Hudson, J. N., Stanley, N. B., Nahata, L., Bowman-Curci, M., & Quinn, G. P. (2017). New Promising Strategies in Oncofertility. *Expert Review of Quality of Life in Cancer Care*(just-accepted).
- Jemal, A., Clegg, L. X., Ward, E., Ries, L. A., Wu, X., Jamison, P. M., . . . Edwards, B. K. (2004). Annual report to the nation on the status of cancer, 1975-2001, with a special feature regarding survival. *Cancer*, 101(1), 3-27. doi: 10.1002/cncr.20288
- Jones, G. L., Hughes, J., Mahmoodi, N., Greenfield, D., Brauten-Smith, G., Skull, J., . . . Bekker, H. L. (2017). Observational study of the development and evaluation of a fertility preservation patient decision aid for teenage and adult women diagnosed with cancer: the Cancer, Fertility and Me research protocol. *BMJ Open*, 7(3), e013219. doi: 10.1136/bmjopen-2016-013219
- Kim, J., Deal, A. M., Balthazar, U., Kondapalli, L. A., Gracia, C., & Mersereau, J. E. (2013). Fertility preservation consultation for women with cancer: are we helping patients make high-quality decisions? *Reprod Biomed Online*, 27(1), 96-103. doi: 10.1016/j.rbmo.2013.03.004
- Knops, A. M., Goossens, A., Ubbink, D. T., Legemate, D. A., Stalpers, L. J., & Bossuyt, P. M. (2013). Interpreting patient decisional conflict scores: behavior and emotions in decisions about treatment. *Med Decis Making*, 33(1), 78-84. doi: 10.1177/0272989X12453500
- LeBlanc, A., Kenny, D. A., O'Connor, A. M., & Legare, F. (2009). Decisional conflict in patients and their physicians: a dyadic approach to shared decision making. *Med Decis Making*, 29(1), 61-68. doi: 10.1177/0272989X08327067
- Lee, S. J., Schover, L. R., Partridge, A. H., Patrizio, P., Wallace, W. H., Hagerty, K., . . . American Society of Clinical, O. (2006). American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol*, 24(18), 2917-2931. doi: 10.1200/JCO.2006.06.5888
- Li, A., Pasternak, M., Duke, C., Johnson, J. V., Leung, K., Cohen, M. G., & Pal, L. (2015). The Effect of Practitioner Education on Fertility Preservation Awareness, Perception, and Clinical Practice [27]. *Obstetrics & Gynecology*, 125, 8S-9S.
- Liamputtong, P. (2011). *Focus Group Methodology: Principles and Practice*. Los Angeles, CA: Sage.
- Loi, K., Lau, M., Loh, S. F., Tan, Y. Y., Hong, G. S., Chan, M. Y., & Tan, A. M. (2010). Attitudes toward fertility preservation in female cancer patients. *J Reprod Med*, 55(9-10), 411-416.

- Loren, A. W., Mangu, P. B., Beck, L. N., Brennan, L., Magdalinski, A. J., Partridge, A. H., . . . American Society of Clinical, O. (2013). Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol*, *31*(19), 2500-2510. doi: 10.1200/JCO.2013.49.2678
- Maltaris, T., Seufert, R., Fischl, F., Schaffrath, M., Pollow, K., Koelbl, H., & Dittrich, R. (2007). The effect of cancer treatment on female fertility and strategies for preserving fertility. *Eur J Obstet Gynecol Reprod Biol*, *130*(2), 148-155. doi: 10.1016/j.ejogrb.2006.08.006
- Marteau, T. M., & Dormandy, E. (2001). Facilitating informed choice in prenatal testing: how well are we doing? *Am J Med Genet*, *106*(3), 185-190. doi: 10.1002/ajmg.10006
- Meneses, K., McNees, P., Azuero, A., & Jukkala, A. (2010). Development of the Fertility and Cancer Project: an Internet approach to help young cancer survivors. *Oncol Nurs Forum*, *37*(2), 191-197. doi: 10.1188/10.ONF.191-197
- Mersereau, J. E., Goodman, L. R., Deal, A. M., Gorman, J. R., Whitcomb, B. W., & Su, H. I. (2013). To preserve or not to preserve: how difficult is the decision about fertility preservation? *Cancer*, *119*(22), 4044-4050. doi: 10.1002/cncr.28317
- Nelson, W. L., Han, P. K., Fagerlin, A., Stefanek, M., & Ubel, P. A. (2007). Rethinking the objectives of decision aids: a call for conceptual clarity. *Med Decis Making*, *27*(5), 609-618. doi: 10.1177/0272989X07306780
- Nicholas, Z., Butow, P., Tesson, S., & Boyle, F. (2016). A systematic review of decision aids for patients making a decision about treatment for early breast cancer. *Breast*, *26*, 31-45. doi: 10.1016/j.breast.2015.12.007
- O'Brien, M. A., Whelan, T. J., Villasis-Keever, M., Gafni, A., Charles, C., Roberts, R., . . . Cai, W. (2009). Are cancer-related decision aids effective? A systematic review and meta-analysis. *J Clin Oncol*, *27*(6), 974-985. doi: 10.1200/JCO.2007.16.0101
- O'Connor, A. M. (1993). Decisional conflict (specify). In G. K. McFarland & E. A. McFarlane (Eds.), *Nursing Diagnosis and Intervention* (3rd ed., pp. 468-477). St. Louis, MO: Mosby.
- Packer-Muti, B. (2010). Conducting A Focus Group. *The Qualitative Report*, *15*(4), 1023-1026.
- Partridge, A. H., Gelber, S., Peppercorn, J., Sampson, E., Knudsen, K., Laufer, M., . . . Winer, E. P. (2004). Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*, *22*(20), 4174-4183. doi: 10.1200/JCO.2004.01.159
- Peate, M., Meiser, B., Cheah, B. C., Saunders, C., Butow, P., Thewes, B., . . . Friedlander, M. (2012). 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*, *106*(6), 1053-1061. doi: 10.1038/bjc.2012.61
- Peate, M., Meiser, B., Friedlander, M., Saunders, C., Martinello, R., Wakefield, C. E., & Hickey, M. (2011a). Development and pilot testing of a fertility decision aid for young women diagnosed with early breast cancer. *Breast J*, *17*(1), 112-114. doi: 10.1111/j.1524-4741.2010.01033.x
- Peate, M., Meiser, B., Friedlander, M., Zorbas, H., Rovelli, S., Sansom-Daly, U., . . . Hickey, M. (2011b). It's now or never: fertility-related knowledge, decision-making preferences, and treatment intentions in young women with breast cancer--an Australian fertility decision aid collaborative group study. *J Clin Oncol*, *29*(13), 1670-1677. doi: 10.1200/JCO.2010.31.2462
- Peate, M., Meiser, B., Hickey, M., & Friedlander, M. (2009). The fertility-related concerns, needs and preferences of younger women with breast cancer: a systematic review. *Breast Cancer Res Treat*, *116*(2), 215-223. doi: 10.1007/s10549-009-0401-6



- Quinn, G. P., Vadaparampil, S. T., Bell-Ellison, B. A., Gwede, C. K., & Albrecht, T. L. (2008). Patient-physician communication barriers regarding fertility preservation among newly diagnosed cancer patients. *Soc Sci Med*, *66*(3), 784-789. doi: 10.1016/j.socscimed.2007.09.013
- Quinn, G. P., Vadaparampil, S. T., Gwede, C. K., Miree, C., King, L. M., Clayton, H. B., . . . Munster, P. (2007). Discussion of fertility preservation with newly diagnosed patients: oncologists' views. *J Cancer Surviv*, *1*(2), 146-155. doi: 10.1007/s11764-007-0019-9
- Schover, L. R., Brey, K., Lichtin, A., Lipshultz, L. I., & Jeha, S. (2002). Knowledge and experience regarding cancer, infertility, and sperm banking in younger male survivors. *J Clin Oncol*, *20*(7), 1880-1889. doi: 10.1200/JCO.2002.07.175
- Schover, L. R., Rybicki, L. A., Martin, B. A., & Bringelsen, K. A. (1999). Having children after cancer. A pilot survey of survivors' attitudes and experiences. *Cancer*, *86*(4), 697-709.
- Stacey, D., Legare, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., . . . Wu, J. H. (2014). Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*(1), CD001431. doi: 10.1002/14651858.CD001431.pub4
- Stiggelbout, A. M., Molewijk, A. C., Otten, W., Van Bockel, J. H., Bruijninx, C. M., Van der Salm, I., & Kievit, J. (2008). The impact of individualized evidence-based decision support on aneurysm patients' decision making, ideals of autonomy, and quality of life. *Med Decis Making*, *28*(5), 751-762. doi: 10.1177/0272989X08321680
- Thewes, B., Meiser, B., Taylor, A., Phillips, K. A., Pendlebury, S., Capp, A., . . . Friedlander, M. L. (2005). Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *J Clin Oncol*, *23*(22), 5155-5165. doi: 10.1200/JCO.2005.07.773
- Tschudin, S., & Bitzer, J. (2009). Psychological aspects of fertility preservation in men and women affected by cancer and other life-threatening diseases. *Hum Reprod Update*, *15*(5), 587-597. doi: 10.1093/humupd/dmp015
- Tschudin, S., Huang, D., Mor-Gultekin, H., Alder, J., Bitzer, J., & Tercanli, S. (2011). Prenatal counseling--implications of the cultural background of pregnant women on information processing, emotional response and acceptance. *Ultraschall Med*, *32* Suppl 2, E100-107.
- von Wolff, M., Montag, M., Dittrich, R., Denschlag, D., Nawroth, F., & Lawrenz, B. (2011). Fertility preservation in women--a practical guide to preservation techniques and therapeutic strategies in breast cancer, Hodgkin's lymphoma and borderline ovarian tumours by the fertility preservation network FertiPROTEKT. *Arch Gynecol Obstet*, *284*(2), 427-435. doi: 10.1007/s00404-011-1874-1
- Wilkes, S., Coulson, S., Crosland, A., Rubin, G., & Stewart, J. (2010). Experience of fertility preservation among younger people diagnosed with cancer. *Hum Fertil (Camb)*, *13*(3), 151-158. doi: 10.3109/14647273.2010.503359
- Yee, S. S.-M. (2015). *Using an Integrated Decision-Making Framework to Identify Factors Associated with Receipt of a Fertility Consultation by Canadian Female Cancer Patients*. University of Toronto.
- Zebrack, B. J., Casillas, J., Nohr, L., Adams, H., & Zeltzer, L. K. (2004). Fertility issues for young adult survivors of childhood cancer. *Psychooncology*, *13*(10), 689-699. doi: 10.1002/pon.784