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Women more vulnerable than men when facing risk for treatment-induced infertility: A qualitative study of young adults newly diagnosed with cancer

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ABSTRACT

Background. Being diagnosed with cancer constitutes not only an immediate threat to health, but cancer treatments may also have a negative impact on fertility. Retrospective studies show that many survivors regret not having received fertility-related information and being offered fertility preservation at time of diagnosis. This qualitative study investigates newly diagnosed cancer patients' experiences of fertility-related communication and how they reason about the risk of future infertility.

Material and methods. Informants were recruited at three cancer wards at a university hospital. Eleven women and 10 men newly diagnosed with cancer participated in individual semi-structured interviews focusing on three domains: experiences of fertility-related communication, decision-making concerning fertility preservation, and thoughts and feelings about the risk of possible infertility. Data was analyzed through qualitative content analysis.

Results. The analysis resulted in three sub-themes, 'Getting to know', 'Reacting to the risk' and 'Handling uncertainty', and one main theme 'Women more vulnerable when facing risk for infertility', indicating that women reported more negative experiences related to patient-provider communication regarding fertility-related aspects of cancer treatment, as well as negative emotional reactions to the risk of infertility and challenges related to handling uncertainty regarding future fertility. The informants described distress when receiving treatment with possible impact on fertility and used different strategies to handle the risk for infertility, such as relying on fertility preservation or thinking of alternative ways to achieve parenthood. The negative experiences reported by the female informants may be related to the fact that none of the women, but almost all men, had received information about and used fertility preservation.

Conclusions. Women newly diagnosed with cancer seem to be especially vulnerable when facing risk for treatment-induced infertility. Lack of shared decision-making concerning future fertility may cause distress and it is therefore necessary to improve the fertility-related communication targeted to female cancer patients.

Being young and diagnosed with cancer in many cases means not only an immediate threat to the health, but also to the future ability to have children, and infertility after cancer has a recognized negative impact on quality of survival [1]. Therefore, internationally used clinical guidelines recommend that fertility-related aspects should be discussed with all patients of reproductive age at time of planning a cancer treatment [2], including options for fertility preservation (FP), such as cryopreservation of sperm, embryos, oocytes or gonadal tissue [3].

Research indicates however that many patients, and women in particular, do not receive adequate information regarding risk for infertility and available FP options [4–6], and that lack of or poor fertility-related communication may cause worries among

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cancer survivors [5,7]. For men, sperm banking has been described as a safety net [8] or as a proof that healthcare providers believed that they had a future and would survive [9], and many women have expressed regrets of not being offered FP [10–12]. Oncologists have stated that lack of knowledge about FP procedures and outcomes, and the desire not to distress the patients are reasons for not starting fertility-related discussions [13]. While many oncologists report that discussions about FP are important, treating the primary cancer is considered more important than FP [14]. According to previous studies, cancer patients are generally positive to receiving fertility-related communication during cancer treatment, irrespective of the level of threat or if FP is available [9,15], but they agree that the primary focus at time of diagnosis is survival [9,12,16,17]. However, most qualitative studies investigating patients' experiences of fertility-related aspects of cancer treatment have been conducted some time (up to 30 years) after diagnosis [5,8,9,11,12,15–18]. Only two studies have been found investigating patients' experiences shortly (within a few weeks) after diagnosis [6,10], one of which focusing on factors affecting the decision-making process concerning FP [6,10].

Even though clinical guidelines state that fertility-related aspects of cancer treatment should be discussed when planning treatment for patients in reproductive age [2], many cancer survivors claim that this was not done in a satisfactory manner [4–6]. It is essential to gain more knowledge about the complex situation arising from being diagnosed with cancer at a young age and receiving a treatment with potential negative impact on fertility. By investigating cancer patients' experiences of fertility-related issues in close connection to the diagnosis new knowledge can be gained, and potential improvements of care might be developed. The aim of the present study was to investigate newly diagnosed cancer patients' experiences of fertility-related communication and their reasoning about the risk of future infertility.

Material and methods

Informants

The informants were recruited between June 2009 and May 2011 at a university hospital in Sweden at three wards specialized in hematology and oncology; the hospital also had a fertility clinic (providing cryopreservation of oocytes, embryos and sperm). Inclusion criteria were: being 20–45 years of age, newly diagnosed with cancer (i.e. within a few weeks following diagnosis), not having a previous history of cancer, planned to receive a treatment regarded as curative and with potential negative impact on fertility, and being able to communicate in Swedish. Recruitment continued until saturation was obtained and few new aspects related to the study aim were added through the interviews. Of 29 eligible individuals who met the inclusion criteria, 21 (10 men and 11 women) agreed to study participation and completed the interview. The majority of those who declined participation indicated that they did not think the topic was important as they were too old or already had the desired number of children.

Procedure

Patients who met the inclusion criteria were identified and approached by the nursing staff at the hospital wards or by a member in the research team, Gabriela Armuand (GA). A letter of invitation outlining the aim of the study, explaining that participation was voluntary, that the participation could be interrupted at any time and that data would be treated confidentially was distributed. Patients agreeing to participate signed a consent form. Those who consented were interviewed at the hospital ward in connection with their chemotherapy treatment, typically during the first weeks of cancer treatment (ranging from 2 days to 12 weeks after diagnosis, median 8.5 weeks). Semi-structured interviews that focused on the area of fertility after being diagnosed with cancer were performed and the informants were encouraged to talk about three domains; how they experienced fertility-related communication, decision-making concerning FP and how they thought and felt about the risk of possibly becoming infertile. Supplementary questions were asked, such as "How do you mean?", "Tell me more" or "How did you feel about that?" when clarification was needed. All interviews were performed by GA, who is a PhD student and registered nurse, and who was not in any way involved in the care of the informants. The interviews lasted between 15 and 51 minutes and were digitally recorded and transcribed verbatim. On the request of three informants, a partner was present at the interview. The partners were not included in the interviews but did occasionally offer their perspective of the experience; these comments were not included in the analysis.

Data analysis

Data were analyzed using qualitative content analysis outlined by Krippendorff [19] and techniques discussed by Graneheim and Lundman [20]. The analysis was carried out in several steps: 1) The transcript of each interview was read several times, to get a sense of each informant's whole story; 2) meaning units (words, sentences, or paragraphs) were identified that related to the study aim; 3) the meaning units were condensed to shorten the text, still retaining the content; 4) each condensed meaning unit was given a code, i.e. a summary of its content; 5) the codes were grouped to form sub-categories and categories; and 6) based on interpretations of meanings in the categories, sub-themes and a main theme were formed. The results are exemplified by citations, clarifications and cut outs (three dots) in the text are marked with square brackets. The authors had several meetings to critically reflect on, and review interpretations of the findings throughout the analysis. The group had different backgrounds including experience of clinical cancer care and reproductive health as well as research.

Ethical considerations

The study was approved by the Regional Ethical Review Board in Uppsala, Sweden. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study. Ethical aspects were discussed in the planning phase of the study and the risk of upsetting patients who had not had any fertility-related communication with their care givers were carefully balanced with the benefits which could be gained through extended knowledge about patients' experiences regarding the issue. While there is no legal requirement for healthcare professionals in Sweden to inform patients specifically about potential risks of infertility from cancer treatment, there are recommendations in both national and regional guidelines to provide patients in reproductive age with this information.

Results

Descriptions of the informants

Eleven women (age 20–41, median 32) and 10 men (age 22–40, median 33) participated. About half of the informants had biological children (n = 12), one woman was pregnant and one male informant's wife was pregnant. A majority of the informants lived in a stable relationship (n = 16) and wanted to have children in the future (n = 15). Their diagnosis included lymphoma (n = 5), breast cancer (n = 4), leukemia (n = 4), testicular cancer (n = 3), ovarian cancer (n = 3), sarcoma (n = 1), and vulvar cancer (n = 1). All informants underwent chemotherapy treatment, in most cases combined with radiation therapy, anti-estrogen treatment, surgery or treatment with antibodies or cytokines.

Thirteen informants recalled having had fertility-related communication with health care professionals (9 men and 4 women) about the impact of the planned treatment on fertility and the grade of the risk of infertility. Only four of the informants had received written information from the hospital on a potential impact of cancer treatment on fertility, and had usually not read the information or studied it closer. In addition, five had searched for information on the Internet, but they had either not found any information or were unsure about the reliability of the information. All but one man recalled having had fertility-related communication with healthcare professionals; most often they were told that sperm production could cease, but that it could return and that the recognized risk for infertility should not be regarded as a contraceptive. They had also received information about FP and seven men chose to cryopreserve sperm. Among the 11 women, only four recalled any communication with professional care givers about the risk for treatment-induced infertility and the risk of premature menopause; two of these women had also received information about FP but none had pursued it. Among the remaining seven women, two had vague recollections of reading about treatment-induced infertility in brochures. Two women who underwent hysterectomy perceived the impact of surgery on their reproductive ability as implicit. The remaining three women became aware of the potential fertility impact of their cancer treatment at first when approached about participating in the present study.

Findings

Although all informants recently had been diagnosed with cancer and were undergoing chemotherapy treatment, many of them described concerns regarding the risk of future infertility. Three sub-themes describe the process of being informed about risk for infertility: 'Getting to know', 'Reacting to the risk' and 'Handling uncertainty' (Figure 1). Through the three sub-themes, a main theme was identified, 'Women more vulnerable when facing risk for infertility', indicating that women reported more negative experiences related to patient-provider communication regarding fertility-related aspects of the cancer treatment, as well as negative emotional reactions to the risk of infertility and challenges related to handling uncertainty regarding future fertility.

Getting to know

The first sub-theme 'Getting to know' concerns how the fertility-related communication was experienced by the informants. The descriptions formed three

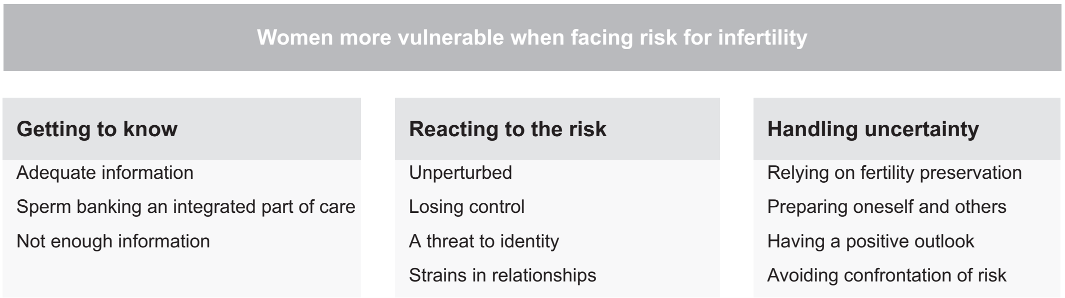

Figure 1. Model illustrating main findings from men and women undergoing cancer treatment.

categories; *'Adequate information'*, *'Sperm banking an integrated part of care'* and *'Not enough information'*. Descriptions of negative experiences in connection with fertility-related communication were predominantly given by women, describing how they had not had enough, if any, fertility-related communication and therefore had unmet informational needs. Male informants described overall more positive experiences; they had had extensive and repeated fertility-related communication with healthcare providers and were encouraged to cryopreserve sperm before treatment.

Adequate information. Statements included in this category described how the informants felt that they had received enough or an extensive amount of information, and sometimes on more than one occasion. They described how the information provider had conveyed a sense of importance; that fertility after cancer was an important issue and that it was important to take action in order to try to prevent infertility. Informants who had taken the initiative to ask questions regarding fertility described how they felt that their questions had been welcomed and that the information provider had taken time to answer them.

> Interviewer: Have you received any information about it [the risk for infertility]?
>
> Informant: Yes, yes, several times I think. [...] Yes, she [the doctor] was talking about it and so... took it up properly. And it was… it's was probably someone else who also did it as well [informed about risk for infertility]. *(Man, age 38)*

Sperm banking an integrated part of care. This category includes statements describing how the process of sperm banking was perceived as an integrated part of the routines included in the cancer treatment. Male informants described how the decision to bank sperm mostly had been made without their involvement; referrals and appointments at the fertility clinic had already been arranged when the issue was brought up by the healthcare professionals. The informants also described how both the decision and the sperm banking were done in haste and that there had been no time for reflection. However, this was sometimes considered as something positive, as there was no time to ruminate.

> I didn't really perceived it [sperm banking] as an option really... it was more like "You're going, on Wednesday morning at eight you'll be there, and freeze [sperm]" Then of cause, people can choose by themselves for sure. But it wasn't something... it wasn't like a question, "Do you want to or not?" rather "It's already booked" and all that, to go up [to the fertility clinic]. [...] I thought it was good. Then you don't have to think about it and to make a choice. *(Man, age 24)*

The informants also described problems that occurred in connection with FP. Some men described how it felt absurd to go and masturbate shortly after receiving the cancer diagnosis and, as a consequence to this feeling, one man had not succeeded banking sperm and was planning to try again in a few days time. Others described how the procedure of sperm banking was embarrassing, and one man described how it had been awkward to have his parents waiting for him outside the fertility clinic, knowing that they knew what he was doing. One man refrained from sperm banking as he had too many physical problems due to the cancer disease. Other men decided to not use FP whereas they already had the desired number of children or did not want to have children at all.

> When you feel as bad as I did... it's no use to think about... trying to satisfy oneself as well [awkward laugh]. Nah, I wasn't up to it ... "But shouldn't you do it, it can be good for future needs" and so on... No, it wasn't possible... But if it hadn't been for the bleedings... then I might have considered it. *(Man, age 39)*

Not enough information. Statements in the category describe how the informants had received very little, none or only written fertility-related information, and that they had unmet informational needs. Some were very upset about this and sometimes tried to make sense of the lack of information by describing internal or external barriers that could be an explanation to this situation. Internal barriers included not having been susceptible for fertility-related communication in the chaotic situation following the cancer diagnosis, or that they maybe had received information but could not recall it. Others described how they did not want to take the initiative to a conversation about fertility as the topic was perceived as sensitive, and instead called for mandatory information sessions focusing on fertility after cancer. External barriers perceived to impede the transfer of information included limited time available for discussion with the physician that forced them to prioritize other questions than fertility, or that it was difficult to identify whom in the healthcare team to ask about fertility issues. Informants also speculated about whether healthcare staff made decisions about information provision based on patients' personal characteristics, such as age or parenthood status.

> There I think they should straighten up [and give information to everyone] [...] But maybe they thought "She's so old, she probably doesn't want more [children]". That they took it for granted. I don't know. *(Woman, age 41)*

The informants also described unmet informational needs including how cryopreservation of oocytes is performed, if there was a need to use contraceptives during the cancer treatment, how to check one's fertility status after completed treatment, and what to do if they did not succeed to conceive after the cancer treatment. Informants also called for more individualized information about their fertile ability after cancer.

> Just things like this, if you need extra hormones or need some estrogens. Yes, a little bit like that. [...] One wants to know how it is. Looking to the future... if one thinks about... future contraception, one has to think about all that. *(Women, age 30)*

Reacting to the risk

The second sub-theme, 'Reacting to the risk' concerns the informants' reactions to the information that the treatment could cause infertility, which was closely linked to the perceived impact of this risk on their plans concerning having children. The informants' descriptions of their thoughts and feelings resulted in four categories: *'Unperturbed', 'Losing control', 'A threat to identity'* and *'Strains in relationships'.* Descriptions about being unperturbed were only given by male informants while descriptions of feelings of losing control and threat to identity were predominantly given by women. Both men and women described strains in close relationships related to their own perceptions of the risk of infertility, as less threatening (men) or more threatening (women) then their family/friends did.

Unperturbed

Informants' statements in this category described how the issue of fertility after cancer was of no or little importance to them at the moment as there were other, more imminent, threats due to the cancer diagnosis. They described how they had thought very little about the issue; they had received information about the risk, been offered FP and had, if they wanted to, made use of it.

> But now it became a little bit of... it ended up in the backwater, so to speak, because the disease itself became the big thing. And this with the fertility and stuff, it doesn't feel like the most important thing. So... well, it wasn't any reaction to it [the risk of infertility], that it was anything very serious, so to say. Especially not when one found out that one could do this saving thing [sperm banking]. Because then you have that possibility, you know. *(Man, age 40)*

Losing control

This category includes descriptions about how the informants felt like they were losing control over their reproductive ability and how this generated feelings of powerlessness. The loss of control in itself was critical; they would no longer be able to make a choice whether to have a child or not. This was also expressed among informants who had no desire to have children in the future. Losing control was also described as being bereaved the ability to have children by not receiving fertility-related information and through this being denied the opportunity to participate in decisions concerning future fertility.

> And would it turn out that I can't [have children], well, it would be hard because then it's like someone... like they're taking something away from you, that you haven't chosen yourself [crying]. When someone else decides for you, that's what I think is bad. Who are you otherwise, if you can't decide for yourself? [crying] *(Woman, age 32)*

A threat to identity

Statements included in this category describe how the informants would have to reevaluate their life goals if they were to become infertile, especially among childless informants. One woman described the risk for treatment-induced infertility as being more devastating than the cancer diagnosis itself, as all her life plans had been based on that she, in the future, would have a family of her own. Others described how they perceived being infertile as being malfunctioning and that their manhood or womanhood was threatened.

> If you look at how it affects your whole life... [crying] Not being able to have children... Would be the worst... absolutely... The absolute worst case scenario, it would almost be worse than if the cancer had spread... actually. *(Woman, age 27)*

Strains in relationships. The descriptions included in this category concerned how the risk of infertility caused strains in the informants' close relationships. Some described how the risk for infertility was more threatening to their partner than to themselves while others described how their worry and sorrow over the risk of infertility was belittled by comments of close friends or relatives who expressed that it was more important to survive than having own children. One female informant blandly stated that her male partner had made clear that he did not consider adoption to be an alternative if they were to have children together in the future. Others described how they feared being abandoned by partners or being rejected by potential future partners; i.e. that infertility would make them less attractive for long-term relationships.

> Informant: I've thought a lot about how people would think about it [the infertility]. I don't know if it will be something negative. [...] It feels like it's something one wants to tell pretty early, if you have a relationship that you feel [is serious].
>
> Interviewer: You said that you wondered if it would be negative. How do you mean?
>
> Informant: Well, if one were to be left for it, so to speak. Perhaps, the other person may feel, "No, I really want my own biological children ", you know. Then it will not work. *(Woman age 23)*

Handling uncertainty

The third sub-theme 'Handling uncertainty' includes descriptions of strategies used by the informants to actively deal with the perceived threats of infertility. The choice of strategies appeared to be based on the perceived significance of risk for infertility, and the level of received information about the risk for infertility and about FP. The sub-theme consists of four categories; '*Relying on fertility preservation', 'Preparing oneself and others', 'Having a positive outlook'* and *'Avoiding confrontation of risk'*. All informants described one or more strategies to actively handle the threat of infertility but as no women used any FP, only men described FP as a strategy to handle the perceived risk for infertility. The descriptions of preparing oneself and others and trying to stay positive were dominated by women whilst both men and women described how they tried to avoid confronting thoughts and feelings about the risk of infertility.

Relying on fertility preservation

This category includes statements describing that informants considered FP predominantly as a solution for potential future infertility, if the treatment would make them unable to have children. They described how they were putting trust in the FP and how the FP had made it possible for them to put the thoughts about the risk for infertility aside; they described the frozen sperm as a 'back-up' and they relied on that the frozen gametes would enable biological parenthood in the future. FP was also perceived as a way of retaining one's ability to choose. In fact, two men chose to freeze sperm even though they did not want any more children, just to keep all options open.

> It's good [to have banked sperm]. It's not like we're going around and planning to become parents in the near future but... Well, it's good to have a backup if there would be problems, you never know really. *(Male, 29 years)*

Preparing oneself and others. The informants' statements included in this category describe how they sought to prepare themselves for potential future infertility by thinking about its consequences and possible solutions, such as adoption or assisted reproduction options. They described how they had told friends and family about the risk for infertility, and how they in turn had received helpful support from them in pursuing more information about the risk and about FP. Friends and family had also been supportive with regard to their plans to adopt or to use donor gametes.

> My boyfriend says that "of cause you'll have your own child" if I want, even if I have to adopt or take a donated egg or something like that. He is totally in to it, what I want to... And my sister says I can get an egg from her if I should need it. *(Woman, age 27)*

Having a positive outlook. This category includes statements around how informants tried to be positive, that they hoped that their body would adjust or that they put faith in God. Some also described how they focused on recovering and were willing to accept the risk of infertility as a price one had to pay in order to survive. Informants who already had children were seeking solace in that fact, and were describing themselves as fortunate compared to those who did not have any children. Others sought solace in that they did not want children anyway, and that the risk for infertility therefore was less threatening.

> Well, it was more shocking that I had cancer than "You will not be able to have children", you know. But of cause one gets worried and a little sad. But one has to hope for the best. I think that first... you just want to get well; this with having children has to wait. But one hopes to be able to have children, and hopes that the body will adapt because I'm so young. *(Woman, age 20)*

Avoiding confrontation of risk

Statements categorized in this category described how informants had put aside their questions and concerns about the risk for future infertility as they just wanted to focus on getting well, they planned to deal with it later, when the cancer treatment was completed. At the moment it was enough just struggling with having been diagnosed with cancer. Some informants described how they had avoided asking questions about the magnitude of the risk for infertility, as they were afraid that the answer would make them upset. Others described how they tried not to think about the risk for infertility and that they did not talk with friends and family about the matter in order to avoid emotional strain.

> Yes it's sad; of course it is… that you may be sterile. It feels like... they'll be taking, sort of… something away from me. You become... [embarrassed laugh] useless... [...] The main thing is that I get healthy. That's what you're most focused on, and then you may see ... The next step, "What will happen when I'm healthy?"... It becomes too much to think about everything at once, so to say. *(Man, age 35)*

Discussion

The results of this qualitative study indicate that the potential loss of the ability to have children after cancer treatment was an important issue among young women and men newly diagnosed with cancer. Many of the informants expressed distress and felt sad over the threat of infertility and described how the risk for infertility was associated with loss of control. The informants used different strategies to actively deal with this threat, such as maintaining a positive outlook and gathering information about alternative ways to parenthood. Women appeared to be more vulnerable than men when facing risk for treatment-induced infertility as their experiences included more disappointment with information provision about the risk and FP options, and more distress about future fertility. Men had an overall more positive experience of communication fertility-related issues than women and they commonly put their trust in sperm banking.

The female informants in this study predominantly described a negative experience of fertility-related communications, and felt that they did not receive enough information and therefore had unmet informational needs. In contrast, the male informants had an overall more positive experience, having received information from healthcare professionals conveying a feeling of importance by encouraging them to bank sperm. This imbalance in received fertility-related information and in the experiences of fertility-related communication between sexes has earlier been reported in both qualitative [6,10] and quantitative research [4,16]. It has been suggested that the more positive experience of fertility-related communication among men is due to having received information without having to ask for it and having been offered FP [16]. Thus, differences in experience of fertility-related communication may not be based on sex differences per se, e.g. that women have higher demands on information or remember information differently, but instead on the quality of the information and the availability of FP option.

Our findings, in line with others [16,21], revealed that FP among men is experienced as an integrated part of the cancer care. Although the men in our study expressed fear for being infertile and experienced infertility as a loss of their manhood, they frequently mentioned how good it was to know that they could have biological children in the future through the frozen sperm. Having banked frozen sperm had helped them to put their concerns about the risk for future infertility aside, as they had a back-up in the freezer. This notion about sperm banking has been reported before, described as an insurance policy for the future [10], a buffer against anxiety over possible future infertility [8] or as a mean to keep options open [21]. However, even though FP for men is a more straightforward procedure compared to FP for women, sperm banking was not described without complications. Men in our study and in earlier studies have described the procedure for sperm banking as absurd or embarrassing [10,21] and that the sperm banking was performed in haste and without any actual decision-making from their part [16]. It is important to be aware of this in the clinical setting and to allow time for decision-making and acknowledge that the procedure of sperm banking can be embarrassing. Offering alternatives, such as taking the sperm sample at home, may be helpful for the patients.

None of the women in our study had the opportunity to undergo FP and therefore this could not be used to cope with the perceived threat of infertility. As a consequence, the women frequently described a feeling of powerlessness and of losing control. It is a known fact that FP for women is more complex than for men. Some of the available methods, such as cryopreservation of embryos or oocytes, require approximately 2–3 weeks to complete the hormonal stimulation [22], and hormonal treatment aimed at retrieving oocytes among women with hormone-sensitive tumors is a concern [22]. However, cryopreservation of ovarian tissue does not require any hormonal treatment, but it is still considered experimental as the number of children born through this technique is small [2]. Research has shown that oncologists sometimes hesitate to inform about FP to women as they are unsure about the effectiveness of FP procedures [6,13,23] and even though the majority of oncologists considered FP as an important issue only between 55% and 67% referred patients to a reproductive medicine specialist [14,24].

In our study, the informants described how their main focus was to cope with the treatment and this has been reported earlier, both among cancer survivors [6,16,21] and healthcare professionals [14,21]. Notwithstanding this some women in our study regarded the threat of infertility as equally distressing as the cancer and described how their worries about future fertility were belittled or ignored by friends and family. If the general attitude is that immediate start of treatment and survivorship is the highest priority, cancer patients who do not incorporate this viewpoint will experience a conflict that can be highly stressful. Earlier studies among healthcare professionals have reported that they sometimes actively discourage women from pursuing FP due to the urgent need of treatment saying that infertility may be a price to pay to survive cancer [10], or signaling that the woman would have a lot to lose and little to gain from pursuing FP [6]. One interesting finding in our study was how the women tried to make sense of why they did receive none or to little information by describing internal and external factor that would explain this, e.g. that the healthcare providers judge them as being too old or not wanting more children. Peddie et al. [6] suggest that the primary barriers for FP is how information about FP is given and the urgent need for treatment. To this, we want to add an even more fundamental barrier, not giving any information at all based on presumptions about patients' priorities and needs. A patient who is not told about the risk for infertility or FP is unable to participate in informed decisions about her/his treatment. The women in our study described how not being included in decisions about their future ability to have children generated feelings of losing control. This experience has been reported earlier [12], where women felt that health services had denied them opportunity to choose by not including them in decision making concerning their future fertility.

Although many of the informants in our study expressed worries and distress over their future ability to have children, none said that they would have preferred not being told about the risk. Earlier research has reported that healthcare professionals sometimes avoid bringing up the issue about risk for infertility with newly diagnosed cancer patients, as they do not want to add insult to injury [13]. But even though the communication around possible infertility can be painful, our study and earlier research indicate that cancer patients in general do want to be informed [9,15,16,18]. However, sensitivity to the individual cancer patient's signals is important when informing about side effects of cancer treatment, including risk for treatment-induced infertility.

Methodological considerations

As we interviewed cancer patients during ongoing cancer treatment we were able to capture their experiences concerning fertility-related matters soon after or during the process of being informed about risk of infertility. We chose individual interviews as the method was suitable for collecting data on personal experiences in a relative unexplored and sensitive area. All interviews were performed at a hospital ward, in a private room, in connection with chemotherapy treatment. While an interview in the informants' home may have created a more private atmosphere, the convenience of being interviewed at the hospital ward was appreciated by the informants. While the fact that a partner was present in three of the interviews may have affected the narratives, these included descriptions of frictions in the relationship due to the risk for infertility.

During the first period of data collection few potential informants were identified, as the staff responsible for recruitment had approached only those patients they knew had received fertility-related information in order to avoid breaking bad news about risk for infertility. After the first author (GA) had taken over the recruitment all eligible patients were approached, including patients who had not had any fertility-related communication with their healthcare providers. Among the informants, three women and one man had no recollection of any discussion about fertility-related aspects of their treatment until they received information about the present study. Even though they were upset about not having received any fertility-related information they expressed appreciation over being included in the study and contributed willingly with their experiences and views. They were encouraged to talk with their physician about the matter and were also offered contact with a psychologist.

To establish trustworthiness in the study, we followed the criteria discussed in the literature and described by Graneheim and Lundman [20,25]. The present inclusion criteria optimized the possibilities to obtain statements that corresponded with the study aim. The variation of diagnosis, sex, age and parenthood status among informants enabled us to capture experiences from several angles and through this achieve higher credibility. All co-authors participated in the analysis and quotations from the interviews were added to further establish credibility. As the data collection was performed over a period of two years there was a risk of inconsistency in the data collection and therefore a threat to the study's dependability, which was limited by the use of an interview guide. The present results may be transferable to young women and men in similar contexts, namely cancer patients starting curative treatment with potential negative impact on fertility at hospitals that provide access to several FP options. The present findings may also have relevance for other contexts or groups, such as young adult patients with other diagnoses who receive treatment with a negative impact on fertility, e.g. patients with multiple sclerosis undergoing stem cell transplantation or patients with rheumatic diseases requiring high doses of NSAIDs or cyclophosphamide. Some of the study findings would benefit from further exploration with a more longitudinal perspective, such as the vulnerability of women and the different strategies in managing the risk of future infertility.

Conclusion

The results of our study show that men and women recently diagnosed with cancer describe distress and feelings of loss when facing the risk for future infertility. Female cancer patients seem to be especially vulnerable as they frequently described disappointment regarding having received no or insufficient information about fertility risks and FP options, and emotional distress regarding their future ability to have children. The fact that available FP methods for women are more demanding and time-consuming than those currently available for men, could be an explanation to the lack of satisfying fertility-related communication between health professionals and female patients. Lack of shared decision-making among women concerning future fertility may cause feelings of losing control and it is therefore necessary to improve the fertility-related communication targeted to female cancer patients. This could include the development and use of decision aids for women diagnosed in child-bearing age, providing adequate time for consultation of fertility aspects and involving partners in these discussions. In addition, patients who desire more information about their future fertility options and FP should be offered consultation with a fertility specialist.

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