Nilsson, J., Jervaeus, A., Lampic, C., Eriksson, L. E., Widmark, C., Armuand, G. M., Malmros, J., Marshall Heyman, M. & Wettergren, L. (2014). 'Will I be able to have a baby?' Results from online focus group discussions with childhood cancer survivors in Sweden. Human Reproduction, 29(12), pp. 2704-2711. doi: 10.1093/humrep/deu280

Human Reproduction, Vol.29, No.12 pp. 2704–2711, 2014
Advanced Access publication on October 24, 2014 doi:10.1093/humrep/deu280

human reproduction

ORIGINAL ARTICLE *Infertility*

'Will I be able to have a baby?' Results from online focus group discussions with childhood cancer survivors in Sweden

J. Nilsson[1,*], A. Jervaeus[1], C. Lampic[1,2], L.E. Eriksson[1,3,4], C. Widmark[5,6], G.M. Armuand[1], J. Malmros[7,8], M. Marshall Heyman[7,8], and L. Wettergren[1]

[1]Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, SE-141 83 Huddinge, Sweden [2]School of Health, Care and Social Welfare, Mälardalen University, SE-721 23 Västerås, Sweden [3]Department of Infectious Diseases, Karolinska University Hospital, SE-141 86 Stockholm, Sweden [4]School of Health Sciences, City University London, Northampton Square, London EC1V 0HB, UK [5]Department of Quality and Patient Safety, Karolinska University Hospital, SE-171 76 Stockholm, Sweden [6]Department of Learning, Informatics, Management and Ethics, Medical Management Center (LIME, MMC), Karolinska Institutet, SE-171 77 Stockholm, Sweden [7]Department of Women's & Children's Health, Childhood Cancer Research Unit, Karolinska Institutet, SE-171 76 Stockholm, Sweden [8]Department of Pediatric Hematology and Oncology, Karolinska University Hospital, SE-171 76 Stockholm, Sweden

*Correspondence address. E-mail: jenny.nilsson.1@ki.se

Submitted on July 4, 2014; resubmitted on September 18, 2014; accepted on September 29, 2014

STUDY QUESTION: What do adolescent and young adult survivors of childhood cancer think about the risk of being infertile?

SUMMARY ANSWER: The potential infertility, as well as the experience of having had cancer, affects well-being, intimate relationships and the desire to have children in the future.

WHAT IS KNOWN ALREADY: Many childhood cancer survivors want to have children and worry about possible infertility.

STUDY DESIGN, SIZE, DURATION: For this qualitative study with a cross-sectional design, data were collected through 39 online focus group discussions during 2013.

PARTICIPANTS/MATERIALS, SETTING, METHODS: Cancer survivors previously treated for selected diagnoses were identified from The Swedish Childhood Cancer Register (16–24 years old at inclusion, ≥5 years after diagnosis) and approached regarding study participation. Online focus group discussions of mixed sex ($n = 133$) were performed on a chat platform in real time. Texts from the group discussions were analysed using qualitative content analysis.

MAIN RESULTS AND THE ROLE OF CHANCE: The analysis resulted in the main category *Is it possible to have a baby?* including five generic categories: *Risk of infertility affects well-being*, *Dealing with possible infertility*, *Disclosure of possible infertility is a challenge*, *Issues related to heredity* and *Parenthood may be affected*. The risk of infertility was described as having a negative impact on well-being and intimate relationships. Furthermore, the participants described hesitation about becoming a parent due to perceived or anticipated physical and psychological consequences of having had cancer.

LIMITATIONS, REASONS FOR CAUTION: Given the sensitive topic of the study, the response rate (36%) is considered acceptable. The sample included participants who varied with regard to received fertility-related information, current fertility status and concerns related to the risk of being infertile.

WIDER IMPLICATIONS OF THE FINDINGS: The results may be transferred to similar contexts with other groups of patients of childbearing age and a risk of impaired fertility due to disease. The findings imply that achieving parenthood, whether or not with biological children, is an area that needs to be addressed by health care services.

STUDY FUNDING/COMPETING INTEREST(S): The study was financially supported by The Cancer Research Foundations of Radiumhemmet, The Swedish Childhood Cancer Foundation and the Doctoral School in Health Care Science, Karolinska Institutet. The authors report no conflicts of interest.

Key words: childhood cancer / infertility / focus group discussions / adolescents and young adults / qualitative research

Introduction

Cancer treatments during childhood can negatively affect fertility in both men and women (Oeffinger and Hudson, 2004; Green *et al.*, 2009). Males may experience reduced sperm production (Hudson *et al.*, 2009) and women may suffer acute ovarian failure or premature menopause, i.e. before the age of 40 (Green *et al.*, 2009). Childhood cancer survivors may also enter puberty later than normal and some may need to have their puberty medically induced (Hudson *et al.*, 2009). Large population-based studies have demonstrated that cancer survivors are less likely to ever have biological children than controls without cancer (Madanat *et al.*, 2008; Hohmann *et al.*, 2011).

A study investigating self-reported health problems among childhood cancer survivors reported fertility problems four times more often than matched healthy controls (Schwartz *et al.*, 2010). Survivors worry about the risk of being infertile (Schover *et al.*, 1999; Stensheim *et al.*, 2011) and the health of future biological children (Langeveld *et al.*, 2004; Zebrack *et al.*, 2004; Thompson *et al*, 2012) as well as their own future health, and have concerns that a pregnancy may induce cancer recurrence (Jacobs and Pucci, 2013). Additionally, partner relationships have been reported to be affected by the risk of infertility (Crawshaw and Sloper, 2010; Gorman *et al.*, 2012). Despite several worries, male and female childhood cancer survivors often have a strong desire to have children (Schover *et al.*, 1999; Reinmuth *et al.*, 2008; Hohmann *et al.*, 2011) and feel hopeful about their chances of having children (Zebrack *et al.*, 2004; Gorman *et al.*, 2012). Still, the information about risk of infertility that is provided by health care professionals is commonly perceived as inadequate (Jacobs and Pucci, 2013).

The survival rate for childhood cancer in Europe is ~80% (Gustafsson *et al.*, 2013; Gatta *et al.*, 2014), leading to a growing population of childhood cancer survivors of childbearing age who may suffer from fertility-related problems. A recent review concludes that the existing qualitative reports focusing on fertility concerns, most often include a mix of persons diagnosed as children and adults and have predominately been performed in the USA (Crawshaw, 2013). One of the few qualitative studies that have been carried out in Europe used a constant comparison method to explore experiences related to fertility in young adults diagnosed with cancer in their teens (Crawshaw and Sloper, 2010). Analysis of the individual interviews resulted in experiences portraying shifting attention in fertility matters: from those not particularly worried or engaged in the issue to those who are very concerned. We want to contribute to the existing body of knowledge about living with a risk of being infertile, a mainly US dominated research field, by investigating the issue among a large group of Swedish childhood cancer survivors who have a clinical risk of infertility. Up to now studies have mainly focused on the situation among those who are most likely to have received some kind of information, i.e. those diagnosed and treated in adolescence and young adulthood, although it has been shown that especially young adult women do not receive sufficient information regarding risk of infertility prior to treatment (Armuand *et al.*, 2012). There is less knowledge about the perceptions of cancer survivors diagnosed at ages when the risk of infertility typically is not communicated to the patients themselves, but to their parents, and it is of great interest to also include their experiences and perceptions of the risk of an impaired fertility. The aim of the present study was to investigate what adolescent and young adult survivors of childhood cancer think about the risk of being infertile and how they reason about having biological children.

Materials and Methods

The study had a qualitative approach with a cross-sectional design. Data were collected by written online focus group discussions. Focus group discussions are generally seen as a method in which the researcher takes advantage of the interaction and communication between participants to generate data (Kitzinger, 1995). The interaction within a focus group format increases the possibility to understand how people think and reason about selected issues, and the group process may be used to clarify participants' views. Regarding sensitive topics, focus group discussions may be advantageous in the sense that more outspoken participants can 'break the ice' and bring forward aspects of the subject to be discussed (Kitzinger, 1995). An online format gives participants the opportunity to be anonymous towards other participants and furthermore, attendance is facilitated as anyone with a computer with internet access can participate (Meier *et al.*, 2006).

Participants

Survivors diagnosed with selected solid tumours (Hodgkin's lymphoma, Ewing/Ewing-like sarcoma, osteosarcoma, rhabdomyosarcoma, neuroblastoma) and tumours of the central nervous system (CNS) during childhood were identified through the nationwide Swedish Childhood Cancer Registry ($n = 400$). Of those, 280 had been treated for solid tumours and 120 for tumours of the CNS. The diagnoses were selected since they are known to have a potential negative impact on fertility, either by the tumour itself (especially CNS tumours) or by the treatment modalities (radiation or chemotherapy in high doses or including alkylating agents). The inclusion criteria were: diagnosed before the age of 18, currently at least 5 years beyond diagnosis, and aged 16–24 at the time of inclusion. Of the 400 persons identified in the register, 31 were excluded due to the following reasons: cognitive impairment ($n = 7$), emigrated ($n = 7$), being abroad ($n = 7$), unidentifiable addresses ($n = 4$), missing personal identification number ($n = 1$), other reasons ($n = 4$) and deceased ($n = 1$); the remaining 369 (262 solid tumours and 107 tumours of the CNS) were approached regarding study participation (Table I).

Table I Demographic and clinical characteristics of participants and non-participants ($n = 369$).

	Participants $n = 134$	Non-participants $n = 235$
Sex, *n* (%)		
Females	68 (51)	103 (44)
Males	66 (49)	132 (56)
Age, median (range)	21 (16–24)	21 (16–24)
Time since diagnosis in years, median (range)	12 (5–23)	13 (5–24)
Age at diagnosis, median (range)	8 (0–17)	7 (0–17)
Diagnosis, *n* (%)		
Tumours of the CNS	31 (23)	76 (32)
Hodgkin's lymphoma	32 (24)	49 (21)
Rhabdomyosarcoma	20 (15)	26 (11)
Neuroblastoma	19 (14)	53 (23)
Osteosarcoma	18 (13.5)	18 (8)
Ewing/Ewing-like sarcoma	14 (10.5)	13 (5)

Data collection

A letter providing information about the study and its procedures was sent to potential participants. The adolescents and young adults were informed that discussions would focus on thoughts around having an intimate relationship as well as possibly having children in the future. Approached participants were subsequently contacted by telephone within 2 weeks after dispatching the letter. Written informed consent was obtained from those who agreed to participate and a suitable time was agreed upon for a group discussion. Each group included two to five participants; an effort was made to mix sexes within groups while striving to form groups with participants of similar ages.

For the purpose of this study an existing internet-based chat platform, which had been developed in collaboration with a consultancy company that had previously been used in research on sensitive issues, was used (Blomberg *et al.*, 2011). Each participant received log-in details by telephone, email or text message prior to the online focus group discussion; access to the chat platform was possible from any computer with internet access. Participants received an alias that they, if wanted, could change to their real name or a pseudonym at the time of log-in. The discussions were performed in real time and lasted approximately one and a half hours. A discussion guide with open-ended questions was developed covering thoughts and experiences of partner relationships, sexual experiences, fertility (covering desire to have children in the future, and thoughts and concerns about the risk of being infertile) and the role of the health care sector in these matters. The guide was flexible and allowed for new questions to be added and included in the remaining data collection. The group discussions started with a short reminder about the purpose of the study, followed by the question 'What did you think when you were invited to participate in this study?' in order to start the discussion. The topic of fertility was typically introduced by the general question: 'What are your thoughts around having children in the future?'; follow-up questions and probing questions were posed based on the answers and interaction among participants in each group, e.g. 'How do you mean?', 'How did you feel about that?'. The discussions were usually led by two moderators (combination of senior researcher and PhD student). Texts from 39 performed group discussions were used for data analysis.

Ethical considerations

The study received approval from the Regional Ethical Review Board in Stockholm, Sweden. All participants were informed that participation was voluntary, that their identity would be kept confidential, and that it was possible to contact the researchers if they felt worried or had issues related to the study prior to, during or after participation. All names in the presentation of results are fictional and the reported ages are approximate in an effort to protect the participants' identities.

Data analysis

Data were analysed with inductive qualitative content analysis as described by Elo and Kyngäs (2008). With such an approach, themes and categories will emerge from the data through the researcher's careful analysis; inductive analysis is considered preferable when the data are fragmented. For this paper, only data regarding thoughts and experiences regarding fertility and having children were analysed. The texts from group discussions were read several times by the first author (J.N.) to get a sense of the whole. Notes and headings were written down in the margin, 'open coding', to cover all aspects of the content that were related to the aim of the present study. Following that, the notes and headings were transferred to a coding sheet and transferred to NVivo software (version 10, QSR International, Melbourne, Australia). The next step was to generate a description of the research topic, 'abstraction', by creating categories, subcategories, generic categories and finally a main category. Seven authors with different research and clinical backgrounds were engaged in the analysis and six of them also contributed as moderators of the group discussions. One advantage of including several researchers in the analytic process is to reduce individual biases (Patton, 1990). The main analysis was performed by J.N., with repeated meetings with all authors involved in the analysis, to discuss the different steps in the analysis and the creation of categories. Quotations in the presentation of the results are given to illustrate different generic categories and interactions between participants. Square brackets with three dots indicate omitted text and if the quotation needs clarification it is given as text within the square brackets.

Results

Profile of participants

Of the 369 potential participants who were approached, 134 accepted participation, and a total of 39 online focus group discussions were held. Of those who declined to participate, 151 did so actively, while 84 did not respond to the information letter or to telephone contact. Demographic and clinical characteristics of participants and non-participants are presented in Table I. The number of participants who currently were raising children was not systematically collected. However, during group discussions five of the participants expressed that they had children (two men and three women); additionally one woman shared that she was pregnant and one man revealed that he was expecting a child with his partner. One online focus group was excluded in the analysis because it only contained one participant.

Findings

The analysis resulted in the main category *Is it possible to have a baby?* and five generic categories: *Risk of infertility affects well-being, Dealing with possible infertility, Disclosure of possible infertility is a challenge, Issues related to heredity* and *Parenthood may be affected* (Table II). All generic categories and subcategories include statements from both male and female participants. The main category illustrates an uncertainty as well as concerns regarding having biological children in the future, due to perceived or anticipated physical and psychological consequences of the cancer experience. The participants varied in the ways they dealt with these worries and also in how they reasoned about the possibility of becoming a parent. Some questioned whether they ought to have children or not, and how parenthood would be affected by physical and psychological consequences of the cancer treatment. In general fertility-related issues needed very little probing and were often brought up by participants themselves. In some cases, participants addressed the issue already when starting the online discussions and in other cases, the subject was discussed after being initiated by the moderator. Overall, the discussions showed that participants differed in their reasoning and thoughts about their fertility and future parenthood.

Risk of infertility affects well-being

Thoughts and feelings regarding the risk of being infertile were brought up in all group discussions and the risk of infertility could be seen as something that affected the participants' lives. Some participants knew that their fertility was impaired or that they were infertile, while others did not know if their fertility status was affected. Participants said that they often thought about their risk of being infertile, some as often as every day. Such thoughts could be triggered by, for

Table II Description of sub-categories, generic categories and main categories.

Sub-category	Generic category	Main category
Knowing that everything works provides a sense of relief	Risk of infertility affects well-being	Is it possible to have a baby?
Negative emotions are aroused in connection with threatened fertility		
Thoughts on fertility always present		
Dealing with uncertainty about one's fertility	Dealing with possible infertility	
Finding out about one's fertility		
Revealing one's endangered fertility	Disclosure of possible infertility is a challenge	
Response to revealing threatened fertility		
Bringing the heredity forward	Issues related to heredity	
No fear of the cancer being inherited		
Worries about heredity		
Alternative solution to parenthood	Parenthood may be affected	
Physical limitations to parenthood		

example, a friend becoming a parent or by receiving information from health care professionals.

> Previously I was only told that it can be difficult to have children, but not why. But now I have found out that I may go through menopause when I am 35. And I have also found out what kind of help I can get, [*fertility preservation*] which I was not told about when I asked before. Ever since then I think about children almost every day. – Woman, age 22, diagnosed at age 13, group 34.

Participants who did not know whether they were fertile or not described it as worrying and thought that finding out they were infertile would be very disappointing, cause anxiety and make one different. Those who had been informed about the risk of possible fertility impairment described this as a disappointment; due to as losing the opportunity to choose to have biological children, as illustrated by a young woman in the quote below.

> My first doctor said that I would not be able to have children in the future. It was like a slap in the face at the time and it is still hard sometimes. When I got transferred to adult care my new doctor said that 'we will see' and that I might be able to have children, but she changes her mind now and then about the possibilities. – Woman, age 21, diagnosed at age 14, group 1.

Those who expressed that they had found out that they were fertile described this as a relief. In a few cases, fertility had been confirmed through a pregnancy, which was described as a positive experience even if the pregnancy was unplanned, as illustrated by the young man below.

> It was very nice [*finding out to be fertile*]. Even if it at the same time, it was really hard and I could not be as happy as I wanted because I wanted to support my girlfriend who thought that an abortion would be really hard. Even if she knew [. . .], we both think we should have planned it [*to have children*], which we hadn't. – Man, age 23, diagnosed at age 15, group 10.

Dealing with possible infertility

Dealing with the risk of infertility included a range of approaches from assuming that one could not have children to taking active steps to investigate the fertility status. One way of reasoning was to hope for the best even if suspecting that the cancer treatment may have impaired fertility. For instance, one participant reasoned that since no radiation treatment had been given, the chance of having biological children was fairly good. Another way of dealing with possible infertility was to have a positive outlook on life, i.e. one could be sad about not being able to have children, but trying to focus on the fact that one is alive and feels fine. Such statements were sometimes used to comfort other participants in the same group who were sad due to the risk of being infertile.

Several participants dealt with the risk of infertility by trying not to hope too much; such a position by participants was thought to minimize the risk of future disappointments. Another way of dealing with uncertainty regarding the risk of being infertile was trying to neutralize the connection between childhood cancer and infertility, e.g. by stating that having children was not a given thing in life and that healthy people with no history of cancer could be infertile too.

> At the same time one shouldn't worry too much; there are many who cannot have children even though they are perfectly healthy. It [*infertility*] can depend on so many things, but sure it is hard to not think and worry about it. – Woman, age 23, diagnosed at age 12, group 34.

Participants who handled uncertainty by initiating investigations to establish if they were likely to be fertile, reasoned that having information about their fertility status was a way to be prepared for the future. Others mentioned that a reason for testing the fertility status was the possibility of not having to use birth control. Testing one's fertility was discussed in several groups and one participant encouraged others to pursue this, as illustrated in the quote below.

> It's [*testing fertility*] worth checking out actually. It was nice to find out [. . .] it could probably be so even if it turns out that you cannot [*have children*]. – Man, age 24, diagnosed at age 17, group 15.

Some participants had decided to postpone actions to find out about their fertility status and reasoned that they did not want to find out until it was time to have children. Other reasons mentioned for not testing fertility were anxiety about the results, fear about how the test

was carried out, and that it could be embarrassing and awkward to discuss these issues with health care professionals.

> I have been treated with radiation and chemotherapy and therefore the fertility may be affected. Sometimes I have thought about testing myself but I feel that I don't want to know if I'm sterile until I'm planning to have children; thus I will keep on living as if everything is completely normal until it is time. – Man, age 23, diagnosed at age 8, group 26.

> I don't know if I want to check it out actually [. . .] because if I got it in writing that I can't have children I would feel so incredibly bad. – Woman, age 22, diagnosed at age 5, group 15.

Disclosure of possible infertility is a challenge

Disclosing the risk of infertility in a partner relationship was generally seen as something difficult and not everybody who had a partner had done so. The explanations for not having shared the risk of fertility impairment were usually that it had not come up for discussion or that the relationship had not been serious enough. Among mentioned obstacles for disclosure were that most people dream about having children and are expecting or planning to have biological children, which caused concerns about how the partner would react. Some participants who knew they were infertile felt as if they had denied their partner a child, which was expressed as something that could make them feel guilty. However, even if some thought it was difficult to disclose a risk of fertility impairment, most participants agreed about the importance of honesty in a relationship. This is exemplified below in a conversation between participants.

> Anna: I think you should be honest with your partner. I met my current boyfriend and I told him pretty early and I knew from the beginning that I wanted to tell him that I might not be able to have children. I wanted him to know directly so that he wouldn't feel betrayed in the future if it was not possible [*to have children*]. And of course you think it's sad that he might not be able to have the future he should have (according to me) because I can't have children. – Woman, age 21, diagnosed at age 14, group 1.

> Peter: I have been in a similar situation as you Anna; I have been with my current girlfriend for almost six months and I told her at an early stage how everything was. Not because I planned marriage at that time but because I didn't want to hide anything. – Man, age 20, diagnosed at age 16, group 1.

> Anna: Yes, you don't want them to feel misled [. . .]. – Woman age 21, diagnosed at age 14, group 1.

When discussing the risk of being infertile, participants often asked each other about what reactions they had experienced when disclosing this risk to a partner. Some did not think it had affected the relationship and that their partners had handled it very well and one participant expressed that it actually had brought them closer together. Others revealed that the partner had had difficulties handling the information; some partners thought more of themselves and in some cases the disclosure had led to the partner ending the relationship. Participants also discussed the optimal timing for disclosing the risk of infertility, as demonstrated in the conversation below.

> Erik: I have a follow up question! At what time in a new relationship should you tell your new partner 'I might not be able to have children because of my disease'. – Man, age 23, diagnosed at age 8, group 26.

> Robin: One should probably say it early but the risk is that many will leave then. – Man, age 21, diagnosed at age 1, group 26.

Issues related to heredity

Descriptions from participants regarding heredity included the importance of having biological children and worries about the risk of cancer heredity. Participants expressed that being able to have a biological child gives one the possibility to recognize family traits and that passing on one's genes was something natural and the way 'we are brought up'.

> It has probably been the most difficult thing. Even today it breaks my heart when I think about it. To be honest, it is horrible. Since my childhood I have dreamt about having children and being able to see similarities. To be able to see similarities has been very important to me. It is really hard to face the fact that I probably never can be pregnant in a natural way [...] –Woman, age 21, diagnosed at age 13, group 5.

Some participants were hesitant about biological children, whether they were fertile or not, as they did not want to risk their child inheriting cancer. While some participants were uncertain if the risk of heredity applied to them, others mentioned that they were not worried since they had received information from health care professionals that there was no risk in this regard.

Parenthood may be affected

Participants reasoned that the risk of fertility impairment affected decisions on how, if and when to become a parent. Adoption was mentioned as an alternative way to have children if biological children would not be an option due to infertility. Some wanted to try for a biological child before considering adoption while a few mentioned that they had considered adoption even before they knew about the risk of infertility. Other participants expressed the opposite, i.e. they did not regard adoption as a good option, since it would not be the same as having a biological child. Other ways to conceive were also discussed, for instance donor insemination, but to a lesser extent.

> I do not worry about not being able to have children; I'm pretty sure that I can. But I feel that I have suffered a lot because of the cancer and I would not be able to go through a pregnancy psychologically. I want to become a parent and that's why adoption is a good option for me in the future. – Woman, age 23, diagnosed at age 14, group 33.

Concerns regarding having enough psychosocial and physical strength to become a parent were discussed in some groups. One participant reasoned that stress tolerance was reduced after undergoing cancer treatment, and another stated that a pregnancy would be too tough to handle psychologically. Others worried about bodily changes due to the treatment, and that it could be challenging for a future child to have a parent that differed from other parents. Some participants also mentioned that they worried about experiencing a relapse of the cancer and if so the child would have to watch them fade away. For female participants, the cancer history affected the choice of when to have children, i.e. the time perspective was crucial as the risk of early menopause created stress and a pressure to have children early in life.

Discussion

The present study investigated thoughts and reasoning about the risk of infertility after being treated for cancer in childhood. Participants actively discussed fertility-related issues, suggesting that the topic is highly relevant for this group. The main category 'Is it possible to have a baby?' illustrates that childhood cancer survivors are affected by the risk of fertility

impairment and the experience of having had cancer. Living with a risk of being infertile was described to have an impact on well-being, intimate relationships and the desire to become a parent or to have biological children in the future. Fertility seemed to be a topic that participants had a need to discuss as they frequently brought it up, and in most cases probing was not needed, in line with previous findings (Kent *et al.*, 2012). The majority of the participants were diagnosed before age ten and, despite the possibility of having no recollection of being treated for cancer, they expressed thoughts about their fertility and had concerns related to the risk of being infertile.

The fertility concerns communicated among the participants in the present study are consistent with findings from both qualitative interview studies (Zebrack *et al.*, 2004; Parry and Chesler, 2005; Crawshaw and Sloper, 2010; Gorman *et al.*, 2012; Kent *et al.*, 2012; Thompson *et al.*, 2012) and quantitative survey studies (Langeveld *et al.*, 2004; Hudson *et al.*, 2009) where participants expressed concerns about fertility or the possibility of having biological children after childhood cancer treatment. Despite uncertainty about their fertility status, several participants expressed a wish to have children in the future, similar to that shown in an interview study (Crawshaw and Sloper, 2010) and large population-based studies (Schover *et al.*, 1999; Reinmuth *et al.*, 2008; Hohmann *et al.*, 2011). Furthermore, the risk of infertility was expressed as a sensitive topic in a partner relationship and could even cause the relationship to end, in line with previous findings (Crawshaw and Sloper, 2010; Gorman *et al.*, 2012; Thompson *et al.*, 2012). Participants in the present study highlighted the importance of being honest with one's partner despite the difficulties of disclosure. Thompson *et al.* (2012) showed that survivors can be reluctant to disclose sensitive personal information such as one's cancer history where the risk of infertility could affect personal intimacy and previously experienced rejection may postpone disclosure (Zebrack *et al.*, 2004). Physical reminders of the cancer experience, such as infertility, can result in problems with self-esteem and may hinder childhood cancer survivors from having intimate relationships (Jacobs and Pucci, 2013). Our results show that intimate relationships represent an important area to address by health care personnel during treatment or follow-up visits, especially when the risk of infertility exists.

Different ways of dealing with the risk of infertility were described, e.g. hoping for the best or trying to neutralize the connection between childhood cancer and infertility. Similar patterns have been described by Crawshaw and Sloper (2010), where participants coped with the risk of fertility impairment by trying to marginalize it and trying to go on as normal. Our results showed that the issue of getting one's fertility status medically examined caused discussion among participants. Some participants, who had tested if they were infertile or not and received positive results, encouraged others to do the same. However, participants who had not examined their fertility status expressed different reasons for this standpoint; some worried that the testing procedure would be embarrassing and others feared the test result itself, while others declared that they had chosen to postpone examination until they decided to have children. Unfortunately, the results do not reveal what investigations participants, who referred to having undergone testing, had performed. Examination with regard to infertility in females and males are today quite standard (Fritz, 2012). The different ways of dealing with possible infertility reflect coping theory with strategies to respond to overwhelming stress, as proposed by Lazarus and Folkman (1984). Not initiating discussions around risk of infertility and postponing examination of one's fertile ability can be seen as avoiding manoeuvres which characterizes emotional-focused coping (Compas *et al.*, 2001). Dealing with the risk by testing one's fertility status and looking at alternative options to achieve parenthood, is in agreement with problem-focused coping, i.e. altering the situation that causes distress. Sperm or oocyte donation as a way to form a family was seldom mentioned by our participants. Possible reasons could be that we did not probe this matter explicitly as well as that participants may not have been aware of alternative methods for having children. Participants rarely mentioned fertility preservation, e.g. cryopreservation, of sperm, oocytes or embryos. Possible reasons for this may be that the majority of the participants were diagnosed in pre-pubertal age and that they were diagnosed up to 23 years ago; hence several fertility preservation options may not have been available prior to their treatment (Dillon and Gracia, 2012).

It was not only the aspect of being infertile due to cancer treatment that was brought up in the group discussions. Uncertainty about having biological children, despite being fertile, was related to worries about cancer heredity and the future health of children, which is consistent with previous results (Schover *et al.*, 1999; Crawshaw and Sloper, 2010; Gorman *et al.*, 2012; Thompson *et al.*, 2012). In our study, participants' thoughts or uncertainty about becoming a parent was also connected to physical or psychological consequences due to having had cancer. Experiences of a low stress tolerance was connected to questioning if it would be to demanding to raise a child or how the child would react to a parent that is physically different (e.g. due to an operation or amputation). To our knowledge, the latter has not previously been discussed in any study. Crawshaw and Sloper (2010) reported that physical conditions, e.g. concentration difficulties, short-term memory loss or mobility impairment, can make childhood cancer survivors dismiss the idea of becoming parents. Thus, the issue of having children was not solely related to the risk of infertility but also to have been diagnosed and treated for cancer.

With respect to trustworthiness of the study, the concepts, credibility, dependability and transferability were used (Graneheim and Lundman, 2004). Credibility was increased by approaching a large sample including women and men with several diagnoses and who differed in age at diagnosis and time since diagnosis. Furthermore, with a high number of participants, different experiences with regard to partner status, reproductive desire, fertility impairment, received fertility-related information and use of fertility preservation, were included, contributing to a broad perspective on the studied phenomenon. Interactions between participants, seen as a strength, when conducting online focus group discussions, allowed different views and opinions related to the discussion topics to be highlighted. Therefore, it is possible for us to say that participants also varied regarding reproductive issues, such as experience of fertility impairment, fertility preservation and biological children. Towards the end of the data collection, we noticed that no new information related to the risk of infertility emerged. This may indicate that we, facilitated by the sample size, had reached informational redundancy (Sandelowski, 1995). Moreover, by using investigator and analysis triangulation, we reduced the risk for researcher bias (Patton, 1990). The online format of the study made it possible to include participants from all parts of the country, urban as well as rural areas. However, younger participants, in general, were less elaborated regarding fertility concerns than older participants. Other limitations that could affect the credibility are the fact that the online chat format may have been

challenging for those with cognitive impairments and may have affected their ability to participate. It also was impossible to observe non-verbal reactions to what was discussed that may have provided additional information. However, some participants stated that they had cognitive impairment or reading/writing disability and some participants used expressions like 'ha ha ha' or smileys to express emotions or reactions. Credibility was also verified with the help of illustrative quotations and agreement among co-authors regarding analysis. To achieve dependability, a discussion guide was developed and gradually improved/changed during the study, but regarding the topic of fertility, almost the same questions were asked in all groups. Regarding transferability, losing the possibility to have biological children or hesitating about becoming a parent are challenges that are not only relevant for those treated for cancer in childhood. It may be possible to transfer our results to other patient groups of childbearing age experiencing disease-related effects on fertility.

Conclusion

Fertility and future parenthood are issues which are highly significant among Swedish childhood cancer survivors. Uncertainty regarding the possibility of having biological children in the future was reported to affect well-being and intimate relationships. Furthermore, physical and psychosocial consequences following cancer treatment were described as reasons to hesitate planning for future children. It is therefore recommended that health care professionals systematically address fertility issues and future parenthood; such communication should include adequate valid information and support.

Acknowledgements

The authors are thankful to all the participants in this study. We want to acknowledge Jenny Juhlin at the Swedish Childhood Cancer Registry for assistance in collecting clinical data.

Authors' roles

L.W., L.E.E. and C.L. planned and designed the study; J.M. and M.M.H. were responsible for selecting the sample. J.N. and A.J. administrated the data collection and the moderators during data collection were J.N., A.J., L.W., C.L., L.E.E. and C.W. J.N. conducted the main part of the analysis while J.N., A.J., L.W., C.L., L.E.E., G.M.A. and C.W. contributed to the interpretation of the analysis, and all authors critically revised the manuscript.

Funding

The Cancer Research Foundations of Radiumhemmet (grant number: 121242), the Swedish Childhood Cancer Foundation (grant number: PRO J11/046), and the Doctoral School in Health Care Science, Karolinska Institutet, financially supported the study. Funding to pay the Open Access publication charges for this article was provided by the Swedish Childhood Cancer Foundation.

Conflict of interest

All authors declare that they have no conflict of interest.

References

Armuand GM, Rodriguez-Wallberg KA, Wettergren L, Ahlgren J, Enblad G, Hoglund M, Lampic C. Sex differences in fertility-related information received by young adult cancer survivors. *J Clin Oncol* 2012;**30**:2147–2153.

Blomberg K, Tishelman C, Ternestedt BM, Tornberg S, Leval A, Widmark C. How can young women be encouraged to attend cervical cancer screening? Suggestions from face-to-face and internet focus group discussions with 30-year-old women in Stockholm, Sweden. *Acta Oncol* 2011;**50**:112–120.

Compas BE, Connor-Smith JK, Saltzman H, Harding Thomsen A, Thomsen AH, Wadsworth ME. Coping with stress during childhood and adolescence: problems, progress, and potential in theory and research. *Psychol Bull* 2001;**127**:87–127.

Crawshaw MA. Psychosocial oncofertility issues faced by adolescents and young adults over their lifetime: a review of the research. *Hum Fertil (Camb)* 2013;**16**:59–63.

Crawshaw MA, Sloper P. 'Swimming against the tide'—the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer. *Eur J Cancer Care* 2010;**19**:610–620.

Dillon KE, Gracia CR. Pediatric and young adult patients and oncofertility. *Curr Treat Options Oncol* 2012;**13**:161–173.

Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;**62**:107–115.

Fritz MA. The modern infertility evaluation. *Clin Obstet Gynecol* 2012;**3**:692–705.

Gatta G, Botta L, Rossi S, Aareleid T, Bielska-Lasota M, Clavel J, Dimitrova N, Jakab Z, Kaatsch P, Lacour B *et al.* Childhood cancer survival in Europe 1999–2007: results of EUROCARE-5—a population-based study. *Lancet Oncol* 2014;**15**:35–47.

Gorman JR, Bailey S, Pierce JP, Su HI. How do you feel about fertility and parenthood? The voices of young female cancer survivors. *J Cancer Surviv* 2012;**6**:200–209.

Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;**24**:105–112.

Green DM, Sklar CA, Boice JD Jr, Mulvihill JJ, Whitton JA, Stovall M, Yasui Y. Ovarian failure and reproductive outcomes after childhood cancer treatment: results from the Childhood Cancer Survivor Study. *J Clin Oncol* 2009;**27**:2374–2381.

Gustafsson G, Kogner P, Heyman M (eds). Childhood Cancer Incidence and Survival in Sweden 1984–2010. *Report 2013 from the Swedish Childhood Cancer Registry*. Karolinska Institutet, 2013.

Hohmann C, Borgmann-Staudt A, Rendtorff R, Reinmuth S, Holzhausen S, Willich SN, Henze G, Goldbeck L, Keil T. Patient counselling on the risk of infertility and its impact on childhood cancer survivors: results from a national survey. *J Psychosoc Oncol* 2011;**29**:274–285.

Hudson MM, Mulrooney DA, Bowers DC, Sklar CA, Green DM, Donaldson SS, Oeffinger KC, Neglia JP, Meadows AT, Robison LL. High-risk populations identified in Childhood Cancer Survivor Study investigations: implications for risk-based surveillance. *J Clin Oncol* 2009;**27**:2405–2414.

Jacobs LA, Pucci DA. Adult survivors of childhood cancer: the medical and psychosocial late effects of cancer treatment and the impact on sexual and reproductive health. *J Sex Med* 2013;**10**(Suppl 1):120–126.

Kent EE, Parry C, Montoya MJ, Sender LS, Morris RA, Anton-Culver H. 'You're too young for this': adolescent and young adults' perspectives on cancer survivorship. *J Psychosoc Oncol* 2012;**30**:260–279.

Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995;**311**:299–302.

Langeveld NE, Grootenhuis MA, Voute PA, de Haan RJ, van den Bos C. Quality of life, self-esteem and worries in young adult survivors of childhood cancer. *Psychooncology* 2004;**13**:867–881.

Lazarus RS, Folkman S. *Stress, Appraisal, and Coping*. New York: Spring Publishing Company, 1984.

Madanat LM, Malila N, Dyba T, Hakulinen T, Sankila R, Boice JD Jr, Lahteenmaki PM. Probability of parenthood after early onset cancer: a population-based study. *Int J Cancer* 2008;**123**:2891–2898.

Meier A, Campbell MK, Carr C, Enga Z, James A, Reedy J, Zheng B. Using the Internet to gather evidence in formative intervention research: a feasibility study of Internet 'chat' focus groups in a study of lifestyle changes in colon cancer survivors. *J Evid Based Soc Work* 2006; **3**:183–200.

Oeffinger KC, Hudson MM. Long-term complications following childhood and adolescent cancer: foundations for providing risk-based health care for survivors. *CA Cancer J Clin* 2004;**54**:208–236.

Parry C, Chesler MA. Thematic evidence of psychosocial thriving in childhood cancer survivors. *Qual Health Res* 2005;**15**:1055–1073.

Patton MQ. *Qualitative Evaluation and Research Methods*, 2nd edn. Newbury Park, CA: Sage, 1990.

Reinmuth S, Liebeskind AK, Wickmann L, Bockelbrink A, Keil T, Henze G, Borgmann A. Having children after surviving cancer in childhood or adolescence—results of a Berlin survey. *Klin Padiatr* 2008;**220**:159–165.

Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995; **2**:179–183.

Schover LR, Rybicki LA, Martin BA, Bringelsen KA. Having children after cancer. A pilot survey of survivors' attitudes and experiences. *Cancer* 1999;**86**:697–709.

Schwartz LA, Mao JJ, Derosa BW, Ginsberg JP, Hobbie WL, Carlson CA, Mougianis ID, Ogle SK, Kazak AE. Self-reported health problems of young adults in clinical settings: survivors of childhood cancer and healthy controls. *J Am Board Fam Med* 2010;**23**:306–314.

Stensheim H, Cvancarova M, Moller B, Fossa SD. Pregnancy after adolescent and adult cancer: a population-based matched cohort study. *Int J Cancer* 2011;**129**:1225–1236.

Thompson AL, Long KA, Marsland AL. Impact of childhood cancer on emerging adult survivors' romantic relationships: a qualitative account. *J Sex Med* 2012. doi: 10.1111/j.1743-6109.2012.02950.x.

Zebrack BJ, Casillas J, Nohr L, Adams H, Zeltzer LK. Fertility issues for young adult survivors of childhood cancer. *Psychooncology* 2004;**13**:689–699.