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## Exploring childhood cancer survivors' views about sex and sexual experiences –findings from online focus group discussions

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### ABSTRACT

**Purpose:** To explore childhood cancer survivors' views about sex and sexual experiences and, as an additional aim, their possible needs for care and support from health care professionals regarding sexual life.

**Methods:** Written online focus group discussions were performed with survivors of childhood cancer, identified through the Swedish Childhood Cancer Registry; 133 (36%; aged 16–25) participated. Written text was analysed using qualitative content analysis.

**Results:** The analysis resulted in one main category: *Could my cancer experience have an impact on my sexual life?* with four generic categories: *Sex considered to be good*, *Feeling insecure and falling behind*, *Relating sex to a stable relationship* and *Concerns related to the physical body*. In general, participants had not reflected on the possibility that their cancer experience could impact on sexual life. Sex was often considered to be something natural, important and taken for granted. However, thoughts and worries were expressed including being shy, feeling insecure and falling behind peers. Physical concerns included vaginal dryness and difficulties related to erection and reaching orgasm. Many participants stated that sexual issues had not been discussed with health care professionals, however, the need for such support differed.

**Conclusions:** Many of the childhood cancer survivors' did not relate their sexual experiences to previous cancer treatment. However, problems were expressed, both of emotional and physical nature. Many participants stated that they had not received any information or support regarding sexual issues from health care professionals, why it is recommended to be regularly addressed in follow-up care.

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## 1. Background

A satisfactory sexual life is important for people's health and well-being (National Institute of Public Health (2012)). Sexuality becomes more central during adolescence (Helmius, 2010) and is a central part of every individual's desire and opportunities for intimacy (Bolte and Zebrack, 2008). The World Health Organization

(WHO) has presented a working definition of sexuality as follows:

*Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.*

(World Health Organization (WHO), 2006) (Page 5).

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Undergoing cancer treatment during childhood may have a negative impact on survivors sexual life (Jacobs and Pucci, 2013). Ovarian, testis and cranial exposure to radiation and certain types of chemotherapy (alkylating agents) can result in delay to or absence of puberty, affecting libido, sexual maturation and erectile function (Armstrong et al., 2009; Haddy and Haddy, 2010). Surgery may also be part of the treatment regimen e.g. removal of the tumour or the affected organ (Haddy and Haddy, 2010) resulting in scars which can affect body image. A changed physical appearance might result in lower sexual confidence and a feeling of being unattractive (Langeveld and Arbuckle, 2008).

Previous research results, mainly from quantitative studies, indicate that survivors are significantly older than their peers at first sexual intercourse (Stam et al., 2005). Furthermore, cancer treatment during adolescence, compared to during childhood, is associated with significant delays in psychosexual milestones including dating and sexual intercourse (van Dijk et al., 2008). Aspects of sexual dysfunction, including lack of sexual interest, decreased arousal, difficulties with erection and ejaculation, orgasm dysfunction, dyspareunia and vaginismus (Fugl-Meyer and Fugl-Meyer, 2010) have not been extensively studied among survivors of childhood cancer. Existing reports indicate that 20–29% of childhood cancer survivors experience their sex life as limited or report sexual dysfunction (Bober et al., 2013; van Dijk et al., 2008) and that sexual dysfunction is more common among older survivors (Bober et al., 2013; Zebrack et al., 2010). A recent study among a large group of adult female survivors of childhood cancer (aged 18–51 years at time of study and 0–20 years at diagnosis) showed that they, compared to siblings, reported lower sexual functioning (Ford et al., 2014).

Although sexuality is a subject where health care professionals, meeting persons with a cancer experience, can play an important role (National Institute of Public Health (2012)), it has been shown that health care professionals often avoid addressing sexuality or sexual dysfunction when talking to cancer survivors, who may not bring the subject up themselves (Bolte and Zebrack, 2008; Park et al., 2009a, 2009b). Research focussing on the sexual life of survivors of childhood cancer indicates that problems related to sexual functioning exist at least in survivors when reaching older age. However, there is a particular lack of qualitative studies that clarify how these young people view their situation and what their needs are in adolescence and young adulthood under 25 years of age. Therefore, the aim of this study was to explore childhood cancer survivors' views about sex and sexual experiences and, as an additional aim, their possible needs for care and support from health care professionals regarding sexual life.

## 2. Material and methods

Data regarding sex and sexual experiences and were collected through written online focus group discussions (FGDs) with synchronous (in real time) participation, using a chat platform. Data were also collected regarding fertility issues and results of this are presented elsewhere (Nilsson et al., 2014). The focus group method has been shown to be advantageous when collecting data concerning potentially sensitive topics (Elmir et al., 2011). A previous study that included patients, parents and survivors (aged 10–19 years) revealed that online group discussions, in this case performed asynchronously, were a useful methodology in paediatric oncology settings (Tates et al., 2009). A well-performed group discussion can move beyond one-to-one interviews by illustrating attitudes, beliefs and different perspectives through the interactions between the participants (Willis et al., 2009).

Qualitative description was used as described by Sandelowski

(2000, 2010) with the theoretical foundation of naturalism and the intention to stay as close to the data as possible (Sandelowski, 2010). According to Sandelowski (1994) the goal of qualitative and nursing research is to get as close as possible to the experience of the human being.

### 2.1. Ethical considerations

Ethical approval was obtained from the Regional Ethical Review Board in Stockholm. Sex can be considered a sensitive issue; it was therefore stressed that participation was, voluntary, and could be terminated at any time. The mode of data collection made it possible for participants to remain anonymous to each other, with only information regarding the existence of a cancer experience being provided to other participants.

### 2.2. Participants

Survivors of childhood cancer who had been diagnosed with selected solid tumours and tumours of the central nervous system (CNS) were identified through the nationwide Swedish Childhood Cancer Registry. We chose to approach a large group of survivors ( $n = 400$ ), on the basis that quite many survivors might decline to participate due to the possible sensitivity of the topic. As the unit of analysis was each FGD, a minimum of 20 units, i.e. FGDs, was desired and it was not known beforehand how many participants would be suitable for each group. Diagnoses Hodgkin's lymphoma, Ewing/Ewing-like sarcoma, osteosarcoma, rhabdomyosarcoma, neuroblastoma and tumours of the CNS were selected with regard to the diagnosis itself or the treatment having a potentially negative impact on fertility. Inclusion criteria were that survivors were aged 16–24 years and at least five years had elapsed since their diagnosis. All those listed in the register as having solid tumours ( $N = 280$ ) and meeting the inclusion criteria were selected. Those treated for tumours of the CNS were randomly selected ( $n = 120$ , from a total sample of  $N = 529$ ). Thirty-one persons were excluded for the following reasons: different disabilities such as cognitive ( $n = 8$ ), emigrated ( $n = 7$ ), being abroad ( $n = 7$ ), unidentifiable address ( $n = 4$ ), missing personal identification number ( $n = 1$ ), deceased ( $n = 1$ ) and other reasons such as undergoing cancer treatment ( $n = 3$ ). Among the remaining 369 eligible participants, 133 (36%) agreed to participate and 235 declined, actively or passively. One discussion included only one participant and was therefore not included in the analysis.

### 2.3. Data collection

An information letter about the aims and procedures of the study was sent by postal mail to eligible participants who were then contacted by telephone within two weeks. Written informed consent was obtained from those agreeing to participate and a suitable time for the discussion was agreed upon. To facilitate the discussion about the possible sensitive topics (sex and fertility), we tried to organise the groups according to age, since sexual experiences may vary between those who are 16 or 25 years old. Two to five persons participated in each discussion with moderator and, to increase the variation in the groups, efforts were made to include participants of both genders in each group discussion. Participant received their log-in details before the discussion and was informed that they were free to choose to use either their first name or a pseudonym. The discussions were performed using an existing chat platform developed in cooperation with an internet consultancy company and used in previous research on sensitive topics (Blomberg et al., 2011a). The platform allowed participants to access the discussion from any computer with an internet

connection. A discussion guide with the general topics to be covered (romantic relationships, sexuality and fertility issues) was developed by the authors inspired by existing literature in the area e.g. Flynn et al. (2011) and previous research using the same mode for collecting data (Blomberg, et al., 2011a; Blomberg et al., 2011b). The discussion guide included questions designed to reveal thoughts and feelings about sexual experiences or associated with having no sexual experiences and about possible sexual problems, e.g. How does the cancer experience affect you when it comes to being intimate and naked with someone? What are your experiences of sex? There are some cancer medications/treatment that can affect sex life-is this something you have thought about? Have the health care professionals that you have been in contact with talked to you about sex and relationships? How do you perceive the support given by the health care professionals regarding relationships and intimacy? How would you have liked to receive support? Follow-up questions or probing questions were asked based on the interaction and discussion among participants. The discussion guide was flexible and continuously developed during the study. The FGDs lasted approximately 90 min and involved one or two moderators with different professional backgrounds (nurses, psychologist and midwife) and clinical experience e.g. counselling in cancer care. After each FGD, participants could evaluate the discussion and also continue the discussion online with participants from the same FGD in a separate chat forum; these results will be presented elsewhere. Thirty-nine online FGDs were performed and the each participant received a cinema ticket as a form of gratitude.

#### 2.4. Data analysis

This was performed using qualitative inductive content analysis (Patton, 2002); the inductive approach is recommended when previous knowledge about a phenomenon exists to a limited extent (Elo and Kyngäs, 2008). The software NVivo 10 (QSR International) was used and all transcripts were transferred from the chat platform into NVivo. These were read and notes and headings were written down using the coding function in NVivo (open coding), followed by grouping under preliminary categories. The subsequent abstraction process involved creating a description of the research topic by collapsing, keeping or changing the categories into sub-categories, generic categories and a main category, trying to keep categories mutually exclusive (Elo and Kyngäs, 2008; Juvani et al., 2005). In addition, in order to describe the overall prevalence of problems related to sexual life, FGDs were categorised according to whether or not such problems were mentioned in the FGDs (Krippendorff, 2004). Findings regarding information were analysed separately. The authors acted as moderators and all were engaged in the data collection and in the discussion of sub-categories and categories until reaching consensus. Verbatim quotes were selected to illustrate findings without distorting or misrepresenting their meaning; three ellipsis dots with a parenthesis (...) indicate omitted words or sentences from quotations, or other participants filling in. Efforts have been made to conceal or anonymise the participants' identity in the manuscript.

### 3. Results

Socio-demographic characteristics of participants are shown in Table 1. Results regarding sex and sexual experiences are presented first, followed by survivors' possible needs for care and support from health care professionals regarding sexual life.

Sexual experiences were discussed in relation to a partner and usually illustrated the current situation five years or more after diagnosis. The analysis resulted in one main category: *Could my cancer experience have an impact on my sexual life?* with the

following generic categories: *Sex considered to be good; Feeling insecure and falling behind; Relating sex to a stable relationship and Concerns related to the physical body* (Table 2). In general, participants had not reflected on the possibility that their diagnosis and/or treatment could have an impact on sex and sexual experiences. In half of the FGDs ( $n = 20$ ), one or more participants in each group reported problems related to sexual life, e.g. scars that affected them in intimate situations, being tired, feeling unattractive or difficulties related to getting and maintaining an erection. In remaining 19 FGDs, no problems were mentioned.

Most of the time, the atmosphere during the discussions gave an impression that sex was considered to be something natural, important and taken for granted, yet both positive and negative thoughts and experiences around sex and sexual experiences were presented during the discussions. When participants discussed and reasoned about the topic, they appeared to do so in a relaxed manner and even problems and worries were mostly described in an open way.

#### 3.1. Sex considered to be good

Participants commonly described sex in a positive manner, they had positive experiences, were satisfied with their sex life and they liked sex, as illustrated by this young man.

"I lived a 'typical teenage life' with several sexual partners, from what I've understood from many friends I have quite a wide sexual experience". (Man, 23 years, group 31)

Many stated that they did not have any sexual problems, sometimes illustrated with emoticons and laughs when the topic was brought up. Furthermore, participants mentioned that the cancer experience had not made them more reserved so, showing their bodies and having scars was not a problem during sexual activities. Participants stated that they had not considered that certain symptoms could have something to do with the cancer treatment, or that sex and cancer had anything to do with each other. Further, they expressed the view that it was difficult to know if the cancer itself had had any impact on sex, since the cancer experience was an embedded part of their lives and they had nothing else to relate to.

**Table 1**  
Demographic characteristics, relationship status and sexual experience of participants as declared during discussions ( $n = 133$ ).

	Females $n = 67$	Males $n = 66$
Age, median (range)	21 (16–25)	22 (16–25)
Time since diagnosis, years, median (range)	12 (5–23)	13 (5–24)
Diagnosis, $n$		
Tumours of the CNS	16	14
Hodgkin's lymphoma	13	19
Osteosarcoma	13	5
Neuroblastoma	11	8
Rhabdomyosarcoma	7	13
Ewing/Ewing like sarcoma	7	7
Self-reported relationship status, $n$		
Current relationship	28	20
Single	28	34
Dating	3	3
Not reported	8	9
Self-reported sexual experience, $n$		
Yes	58	45
No	3	13
Not reported	6	8

**Table 2**

Description of categories, generic categories and the main category.

<b>Main category</b>			
Could my cancer experience have an impact on my sexual life?			
<b>Generic categories</b>			
Sex considered to be good	Feeling insecure and falling behind	Relating sex to a stable relationship	Concerns related to the physical body
<b>Sub-categories</b>			
Positive sexual experience	Limited sexual experience	Focus on the relationship	An altered body
No sexual problems	Insecure about sex	Waiting with sex	Altered desire
	Concerns about ever finding a sexual partner		Feeling dry
	Peer influence		Using aids
	Later sexual debut		Difficulties reaching orgasm
	Sex as a proof of being sexually desirable		Difficulties related to erection and ejaculation

### 3.2. *Feeling insecure and falling behind*

Emotional descriptions concerning feeling insecure and falling behind were brought up, where participants quite openly revealed their thoughts. Other descriptions were more like a statement e.g. “I’m still a virgin”, or expressions such as “Sex is not the most important thing in life at the moment” (man, 18 years, group 27). Sometimes other participants replied and asked further questions or had a different opinion but not often. A 21-year-old participant from the same group discussion as the man contributing the previously cited quotation (group 31) described quite a different experience to him.

“No I don’t live a ‘typical teenage life’... because I get tired and can’t live like other teenagers” (...) “so I have only had sexual experience with my boyfriend.”

A desire to have sex was expressed by some of those who were inexperienced but they also indicated that the thought of the first time was linked to nervousness. Others described being shy and feeling insecure about how to do it, which had had an impact on their sexual experiences.

“My sexual experiences are limited if I compare myself to my class mates, I wish it weren’t so. When it comes to taking the step I get shy or scared, after having been talkative and having no problems at all to chat and have a great time.”

Man, 22 years (group 34)

Concerns about never finding a sexual partner were described by some participants. For one woman, whose leg had been amputated, the greatest worries during the first years after diagnosis were related to never finding a partner or someone who would want to have sex with her. She had experienced feelings like “this was like the end of life” (woman, 21 years, group 5). Another participant, a 23-year-old man (group 25), illustrated his situation as below:

“I remember when I was in my early teens I thought my life would be hell because of the cancer, I saw myself as being a virgin and a bachelor forever, today I know it isn’t like that but if I’d had the opportunity to talk to someone older who had been in my situation I could have got rid of those thoughts.”

Peer influence was described as a fear of falling behind others and negative feelings related to limited sexual experience when in an environment where sex was a frequent topic of conversation. Below is an example of the interaction process where a woman responded in a supportive way to a man with worries related to limited sexual experiences (group 13).

Man (16 years old): “In a way it would be great to get laid, I’m pretty tough as a person and sometimes I have to deal with that when it comes to stuff about sex (among friends). But it’s OK. “ (...)

Woman (17 years old): “But you seem like a nice guy so it will work out!”

One participant described a late sexual debut in terms of being a “late bloomer”, but that did not influence their present sex life that much. Part of one interaction below (group 35) illustrates participants’ sometimes different views and reasoning concerning sex. On the one hand, this was connected to being behind others, but on the other hand, there was the view that it was the peers who were behind, since they did not have the same experience.

Woman 1 (24 years old): “When it comes to sex I was very late with that, and in the end I did it just to be the same as the others, haha, maybe pretty usual for teenagers.”

(...)

Woman 2 (21 years old): “Haha. Exactly the same for me”

Woman 3 (23 years old): “This is interesting, I experienced the complete opposite. I had been through something different from everybody else and I felt like my friends were often very far behind, haha (no hard feelings).”

Another aspect included women who talked about using sex or having one-night stands as a mean of proving to themselves that they were, or still are, sexually desirable.

“I have had quite a lot of one-night stands, especially after I got started so to speak, it was very much to prove to myself that I could, if you know what I mean? Because I was so late with everything, and because guys suddenly noticed me. They didn’t when I was sick. Then I was just the one to feel sorry for” (Woman 24 years, group 35)

### 3.3. *Relating sex to a stable relationship*

Some participants discussed sex in relation to values e.g. that sex should be performed within a stable relationship and also in terms of wanting stability due to the experience. Two participants, one woman and one man also stressed waiting until marriage to have sex.

Man (23 years old): “Do you think that it’s because of to your disease that you haven’t had several sexual partners? I mean, there are other 18–20 year olds that haven’t had sex yet”



Participant (21 years old): “Yes I think so definitely”.

(...)

Participant (21 years old): “Because I want stability and need that”.

(group 31)

### 3.4. Concerns related to the physical body

The descriptions under this generic category related to an altered body, altered desire, feelings of dryness, using aids, difficulties related to getting and maintaining an erection, reaching orgasm as well as ejaculation (Table 2). Sometimes participants explicitly linked the concerns to consequences of the cancer experience/treatment such as difficulties related to erection due to an operation in the genital area, back pain influencing sexual performance, lower sensitivity possibly affecting the ability to reach orgasm, an increased fear of infections (i.e. urinary tract infection) and altered desire due to medications. Some survivors described the situation as a matter of fact without being emotional, while others felt it was difficult being amputated and having visible scars, even if their partners had not reacted negatively. When revealing such intimate issues, other participants in the discussion sometimes replied in a supportive and caring way while others just stated their own situation and did not make any comments about the experiences of others.

Some women described problems and worries related to vaginal dryness that had negatively affected them, such as pain during sexual activities. Usually they did not relate dryness to the cancer experience or treatment given and had no knowledge of any possible impact of cancer treatment on vaginal dryness. However, dryness was described as more embarrassing than using lubricants by one participant, and another woman, 22 years old (group 38) commented as below:

“Yes it's not the first thing you want to do (take out lubricants). But it's not fun having sex if you're dry down there either. The guy often thinks I don't want to or that I'm not 'turned on’”.

Sexual problems were seldom spontaneously linked to medication. However, when we asked about this, some medications were described as negatively influencing sexual desire and related to difficulties reaching orgasm. One male mentioned hormonal disturbances having had a negative impact on sex earlier in life and that changes in medication affected desire and overall well-being. One 24-year-old female (group 16) described her situation as below:

“I have been taking anti-depressants since I got sick. Once a physician mentioned this with regard to sex life and asked if I had difficulties reaching orgasm. I thought it was really good of her to bring it up! I never expect to have an orgasm when I'm with someone.”

Some men talked about difficulties related to erection and ejaculation, either due to an operation or due to performance anxiety. During one online discussion it was mentioned that talking about erectile dysfunction was hard and not a discussion you wanted to have with anybody.

### 3.5. Care and support

The findings regarding survivors' possible needs for care and support from health care professionals regarding sexual life were

analysed separately. Many participants stated that they had not received any information or support regarding sexual issues and romantic relationships, some participants also expressed dissatisfaction with not having received any such information. However, some stated that they had not reflected on the role that health care professionals could take in relation to sexual issues or romantic relationships or that they did not have any need to talk about these issues. Positive views of and experiences from the health care sector were expressed, for instance from special youth clinics and follow-up clinics where participants felt that they had received good support regarding romantic relationships and intimacy. Below is an example (group 5) where we explicitly asked about what health care professionals should be aware of when encountering young persons with a cancer experience:

Moderator: “What do you think that health care professionals, who work with young persons' who have experienced cancer treatment during childhood, should be aware of regarding sex and romantic relationships?”

Woman (21 years old): “(...) I think it is important to talk about the future and partners and stuff, already during the treatment phase. (...) And to talk about “grown-up stuff”, if the person is old enough, of course.”

Moderator: “What do you mean by “grown-up stuff”?”

Woman (21 years old): “(...) Sex, guys, girls, periods, jobs, future, feelings.”

## 4. Discussion

The analysis of the written online focus group discussions resulted in the main category; *Could my cancer experience have an impact on my sexual life?* Generally, participants had not reflected upon any possible impact of the cancer diagnosis/treatment on sexual life. In half of the FGDs, one or more participants in each group reported some sort of problem related to their cancer experience.

Many participants described positive feelings concerning their sexuality and sexual experiences and reported that they did not think their experiences had been influenced by the cancer diagnosis and/or treatment. However, the results also revealed participants' thoughts and worries regarding sexual matters while growing up, a period characterised by struggling with self-confidence and self-image. Some of the thoughts, e.g. those concerning self-confidence, self-image and the fear of falling behind peers may be similar to those of young people in general. This is reflected in a Swedish report (Tikkanen et al., 2011) about young persons (15–29 years), where those struggling with low self-esteem had more negative experiences with regard to their latest sexual encounter than the others. However, the majority of participants described their sexual debut and their latest sexual encounter in a positive manner.

Some of our participants discussed sex in relation to values, e.g. that sex should be performed within a stable relationship and also in terms of wanting stability due to the disease experience. Whether these views and attitudes are related to specific cultural and religious beliefs is unknown, but something that could be of interest to further investigate.

Our results also revealed that some participants were disappointed with how health care professionals had addressed sexual matters. According to the literature, it appears as if sexual issues are often avoided by health care professionals, and not addressed in the follow-up care (Bolte and Zebrack, 2008; Park

et al., 2009a, 2009b). A review (Park et al., 2009b) pointed at that patients with cancer would like open communication and permission to discuss sexuality and sexual concerns with health care professionals. They also want to be approached about their sexuality and to have relevant and practical information about sexual life after treatment for cancer as well as anatomy, physiology and treatment effects on sexual functioning (Park et al., 2009b). If health care professionals do not address these issues, patients or survivors may think that sexuality and sexual functioning are not valid concerns. Incorrect beliefs may be persisting, such as cancer is contagious when having sex or that sex may promote recurrence of the cancer diagnosis (Park et al., 2009b). To address sexual issues is also important considering research showing an increase in risky sexual behaviour among chronically ill young individuals (Murphy et al., 2013) leading to an increased risk of sexually transmitted infections (STIs) and unwanted pregnancies.

Why do health care professionals refrain from communicating about sexuality? Research shows that adolescents and young adult with a chronic illness are considered asexual, occupied with diagnosis- and treatment related issues and therefore not interested in social and sexual relationships (Murphy et al., 2013) and if cancer patients are perceived as anxious, physicians initiate discussions about sexual issues to a lower extent. Lack of knowledge, time and uncertainty regarding whose responsibility it is to bring up such issues, might be other barriers (Park et al., 2009b). In addition, uncertainty on how social and cultural factors (such as religious beliefs and social norms) have to be taken into consideration may be additional barriers when understanding and addressing sexual problems.

The descriptions regarding physical concerns can be referred to as definitions of sexual dysfunction (Fugl-Meyer and Fugl-Meyer, 2010) and participants sometimes spontaneously related these to the cancer experience, although usually they did not. Bober et al. (2013) and Zebrack et al. (2010) have reported that the most common sexual dysfunctions among survivors of childhood cancer are lack of interest, difficulties becoming aroused and enjoying sex, and erectile dysfunction. The participants in the present study discussed erectile dysfunction and vaginal dryness but seldom anything about lack of interest, difficulties enjoying sex or pain during sex despite that pain during vaginal intercourse is highly prevalent among young women in Sweden (Elmerstig et al., 2013). We therefore recommend that this subject be further studied, particularly among female childhood cancer survivors also referring to research showing impaired sexual functioning in a long-term perspective among female childhood cancer survivors (Ford et al., 2014). Such research would preferably be performed using a quantitative design to be able to draw conclusions regarding prevalence and knowledge concerning pain and vaginal dryness among females, and erectile dysfunction among males.

#### 4.1. Methodological considerations

Despite some earlier research indicating that sexuality could be a sensitive topic and difficult to discuss in a focus group format (Kent et al., 2012), the present study using online FGDs provided rich material. Overall, the participants were open and interacted well with each other, which is in line with results from another study using focus groups to explore sexual functioning among cancer patients (Flynn et al., 2011). The participants in the present study expressed different views but seldom disagreements. The mode of data collection seems relevant for young persons since it offers the possibility of reaching participants over large geographical distances. The variation in the sample with regard to sexual

orientation is unknown since participants did not explicitly address homo- or bisexual orientation. We also used the more gender-neutral term “partner” throughout the discussions and did not explicitly ask about sexual orientation.

The selection of the diagnoses included in the study was based on the diagnosis itself or the treatment having a potential negative impact on fertility and we do not know if other cancer diagnoses would have revealed more or other problems. However, different treatments and diagnoses were included and also diagnoses previously shown to have an impact on sexual functioning among childhood cancer survivors (Sundberg et al., 2011). In addition, a recent overview by Jacobs and Pucci (2013) states that any combination of surgery, chemotherapy, and/or radiation prior to reproductive age puts childhood cancer survivors at a significant risk for infertility and sexual dysfunction.

We did not explicitly ask questions about lack of interest and enjoyment, which might have contributed to the lack of such findings. Our questions were of a more open and explorative nature allowing the participants to reveal their individual views and experiences, regardless of whether they were negative or positive. In addition, the study method of written FGDs with possibly shorter transcripts, might affect the data obtained as opposed to the method of verbal discussion groups. However, with regard to the topic and the explorative nature of the study, this method was considered preferable. Since the data collection resulted in 39 FGDs, a quantitative approach was also taken to illustrate the prevalence of problems shared in each FGD. Whilst these are not exact figures, it gives an impression of the impact of the cancer diagnosis and/or treatment on sexual life.

The response rate of 36% could be considered reasonable considering the possible sensitive topic. It is also comparable to the response rate (35%) in a recently published Swedish paper, using FGDs to investigate the experiences of teenagers and young adults treated for cancer (Olsson et al., 2015). In the present study, participants of both genders, different ages and time span since diagnosis, with and without sexual experiences/problems and being in a relationship or not, were represented (Table 1), contributing to different perspectives on the topic under study. However, the risk of lack of variation exists, as those who participated could be those most willing to reveal their experiences, either having fewer or more problems. Some of the eligible non-participants gave reasons for why they did not want to participate, such as having left the cancer experience behind, not wanting to talk about it, or that they had been very young at diagnosis and therefore did not think they could contribute. The majority of the FGDs were performed with both genders and this was not anything participants explicitly indicated as being negative in the evaluations. Still, we do not know if same-gender groups would have resulted in different findings and therefore recommend this to be further studied to determine whether certain topics may be easier to discuss with peers of the same gender.

The different experiences and backgrounds of the moderators/authors different also contributed to the credibility of the study. Continuous discussion were held among the moderators/authors during the analysis process, to ensure that the categories covered the data (Graneheim and Lundman, 2004).

The topics and main questions were the same for all participants while the posing and timing of follow-up and probing questions were developed during the process of data collection through a dialogue between the moderators. Acquiring new knowledge of the subject under study while performing data collection strengthens the study and thus, each FGD contributed to a variation in the data material. New aspects of the topic under study emerged throughout the data collection period.



## 4.2. Implications for practice

Based on the results from this study it is recommended that health care professionals regularly address sexual health and intimacy in the follow-up care of adolescent and young adult survivors of childhood cancer. Registered nurses are suggested to take an active part with regards to giving information and support concerning sexual matters especially since there is an association between sexual dysfunction and lower levels of health-related quality of life (HRQoL) (Bober et al., 2013). It is recommended that information concerning possible negative effects on sexual life and intimate relationships are to be communicated even if this, according to age and maturity, may be several years after cancer treatment. One way to initiate the topic, when appropriate, could be by posing an open-ended question such as: "One of the issues that young people in the same situation as you might think about during and/or after cancer treatment is how the cancer treatment may impact on romantic relationships, sexual life and intimacy. Is this something you have thought about?" Additionally, educational material such as a booklet with information regarding sexuality, including cancer-specific issues, and a checklist covering the basic topics (e.g. body image, vaginal dryness, impotence) could facilitate discussions (Geue et al., 2015). Since sexual issues often are avoided by health care professionals and not addressed in the follow-up care (Bolte and Zebrack, 2008; Park et al., 2009a) there appears to exist a need for training how to communicate these issues. There are appropriate models that can be used to guide health care professionals' actions such as the BETTER model (Mick et al., 2004) and the PLISSIT model (Park et al., 2009b). It is also recommended to include this topic in nursing education, both at basic level and for those studying oncology nursing care at an advanced level.

## 5. Conclusion

Many of the childhood cancer survivors' did not relate their sexual experiences to their previous cancer treatment. However, problems were expressed, both of emotional and physical nature. Sex and sexual experiences were usually discussed in a relaxed way during the focus group discussions, regardless of any problems or worries experienced. Many participants stated that they had not received any information or support regarding sexual issues from health care professionals and some also expressed disappointment, why it is recommended that sexual life is regularly addressed in follow-up care.

## Conflict of interest

The authors have no conflict of interest to disclose.

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