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Fertility and cancer—a qualitative study of Australian cancer survivors

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Abstract

Purpose This study aims to assess the fertility concerns among cancer survivors aged 50 and under as part of a larger study investigating the survivors' concerns regarding fertility, sexuality and parenting.

Methods Cancer survivors who were at least 1 month post-treatment were invited to a recorded interview. The patients were identified from an oncology database and invited to participate via letter or during clinic consultation. The participants were recruited until saturation of themes was achieved. Transcripts were coded thematically, with greater emphasis given to frequently raised themes.

Results Twenty-five survivors (19 women) were interviewed. The median age was 37 (range 24–50). Median time since completion of treatment was 7 months. Twenty were married or in a relationship; 18 had children at the time of diagnosis. Two became pregnant after treatment. Four themes were identified: (1) Fertility represents more than child-bearing capacity: potential fertility loss was a concern for participants, irrespective of their desire for future children; (2) Assumed infertility: There was a tendency for participants to assume that they were infertile; (3) Lack of information regarding decision-making and fertility: The respondents reported a perceived lack of consideration of fertility at diagnosis by medical professionals, and this impacted upon the decision-making process; and (4) Participant recommendations: The respondents wanted more information and for support services to be offered.

Conclusions Fertility is an important concern for young cancer survivors. There is a need for strategies regarding information provision and support for cancer patients with regard to these concerns.

Keywords Cancer · Fertility concerns · Survivorship · Cancer treatment

Introduction

The impact of cancer and its treatment on fertility is an important concern for younger cancer survivors [1–8]. Up to 70% of young survivors (defined as aged 50 or under) express a desire for children after treatment [3–5, 9] and are concerned about the possibility of not having biological children in the future as a result of cancer and its treatment [2, 5]. As the age of first pregnancy in the Western world increases (currently approximately 29 years) [10], many young cancer patients may not have completed their families by the time of cancer diagnosis, facing a risk that the cancer treatment may delay any future reproduction to the time when they are older than 40 years when the natural reproductive capacity tends to decline. With the age of natural menopause at approximately 51 years [11] and treatment-induced menopause potentially occurring earlier, young cancer survivors are faced with issues of fertility decline, transition to (often premature) menopause, with resulting impact on sexuality, and, in many cases, parenting of young children and/or decision about future parenthood in the light of cancer diagnosis and treatment. While the changes of fertility and menopause apply predominantly to

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women, male cancer patients are likely to be similarly affected by having female partners in the corresponding age group who may be impacted by the cancer diagnosis in all ways but the direct impact of the cytotoxic drugs. Psychological distress, particularly anger, depression and grief, have been reported among men and women in relation to the potential loss of fertility [2, 5, 12–16]. While fertility-related distress appears to resolve over time for the majority of cancer survivors, persistent long-term distress occurs for approximately 15% [17]. It has been well established that those survivors who are childless at diagnosis and desire future children have great concerns about fertility. However, less is known about survivors who have children at diagnosis and/or who may not have plans for future children. These survivors, by nature of having a family, may not be perceived by the health care providers as needing advice regarding fertility. Indeed a study by Duffy, Allen, and Clark [18] found that women who had children at diagnosis were less likely to recall having a discussion regarding risk of menopause as a result of treatment. The fertility concerns of men have also been substantially less researched than those of women. The present qualitative study investigated the nature of fertility concerns among a diverse cohort of cancer survivors as part of a larger study investigating fertility, sexuality and parenting concerns. The study explored the impact of cancer and cancer treatment on fertility, fertility concerns and their impact and survivors' recommendations regarding strategies that may assist them in dealing with their concerns.

Methods

Participants

Cancer survivors aged 18–50 who were at least 1 month post-treatment were invited to an interview with a trainee psychologist. The patients were identified from the oncology database of a South Australian hospital and contacted by letter or approached by a clinician during clinic consultations. In addition, an advertisement for participants was placed on the website of a cancer advocacy group, Cancer Voices South Australia. Exclusion criteria included evidence of disease progression during the month prior to interview and an inability to speak English. The participants were recruited between August 2009 and May 2010.

Procedure

Individuals who consented to participate were posted or emailed a copy of the questions to be asked in the interview to give them time to consider their answers and encourage a greater depth of discussion. There were ten primary interview questions (see "Appendix 1"). The ten primary questions were supplemented with clarifying and probing questions to encourage more in-depth responses. Twenty interviews (80%) were conducted face to face in a consultation room of a cancer clinic; the remaining five (20%) were interviewed by phone. The median interview length was 45 min and ranged from 19 to 102 min.

All interviews were conducted by a Clinical Psychology Masters student (RP). The participants gave written informed consent before the audio-taped interview. The participants were informed that they had the right to not respond to questions. Each interview commenced with the participants providing some information about their cancer experience and how the diagnosis impacted upon themselves and their family to help them develop rapport with the interviewer. The participants were provided with car parking reimbursement (where required) and a movie voucher as an honorarium. This study was approved by the Southern Adelaide Health Service/Flinders University Human Research Ethics Committee.

Data analysis

Each interview was transcribed verbatim and checked for accuracy against the audio-taped recordings. Thematic analysis was used to analyse the data using the conventional approach [19]. After transcription and reading of the data, two authors (RP and LB) systematically coded the first transcript, discussing each coded statement in order to develop an agreed coding system. One author (RP) then coded the remaining transcripts. The codes were collated intoemergent themes and sub-themes. The themes were reviewed and the thematic "map" was generated, which was then used to define the final themes which formed the basis of the final report reviewed for accuracy by all authors. The results were prioritised according to frequency (raised repeatedly within an interview), extensiveness (raised by more than one participant) and emotiveness (themes raised strong feelings or resulted in a long discussion) [20]. A second author (LB) then independently coded four transcripts to establish inter-rater reliability of data coding, and the coded transcripts were compared for coding consistency. Coding discrepancies were discussed and agreement with regard to the final themes reported was achieved between the two authors.

Results

Participant characteristics

Twenty-five young cancer survivors, 19 female patients and six male patients aged 24–50 (median 37), took part in the interviews. The medical and demographic characteristics of the participants are described in Table 1. The majority had breast cancer (14, 56%) or lymphoma (5, 20%), with the

Table 1 Demographic and medical characteristics of participants

Number of participants	*n*=25
Age, mean (SD)	38.8 (7.52)
Months since completing treatment, median	7.00
Female	19 (76.0%)
Marital status	
Married, pre-diagnosis	20 (80.0%)
Married, post-diagnosis	18 (72%)
Parental status, pre-diagnosis	
No children	7 (28%)
Has biological children only	14 (56%)
Has biological and non-biological children	4 (16%)
Parental status, post-diagnosis	
No children	7 (28%)
Same number of children	16 (64.0%)
Had additional child post-diagnosis	2 (8%)
Tertiary education	15 (60%)
Cancer type	
Breast	14 (56.0%)
Lymphoma	5 (20.0%)
Testicular	3 (12.0%)
Ovarian	1 (4.0%)
Germ cell tumour	1 (4.0%)
Langerhans tumour	1 (4.0%)

remaining cancers including germ cell, testicular, ovarian and Langerhans histiocytosis. Two survivors had a history of two cancers. All survivors had been treated with chemotherapy, 80% with radiotherapy, 80% had undergone surgery and 40% had hormonal therapy. The median time since the completion of treatment was 7 months. The majority had completed a higher education (15, 60%) and they were Australian by birth (19, 76%). Twenty were married or in a relationship (80%); 18 had children at the time of diagnosis (72%). Two became pregnant after cancer treatment. Twelve participants (48%) had a desire for children in the future and seven of these did not have children

Major themes

From the results, four major themes were identified and have been grouped under two subheadings: themes 1 and 2 relate to perceptions of fertility, and themes 3 and 4 relate to information and decision-making issues.

Fertility perceptions

Theme 1: fertility represents more than child-bearing capacity

The most frequently and extensively raised theme regarding fertility perceptions was the fact that fertility represented more to survivors than the ability to reproduce. Fertility loss was a cause of concern for 16 participants, regardless of their desire for future children.

Of these 16 participants, nine (all women) experienced an emotional reaction when they found out that their fertility could be affected by the treatment, despite making the decision before diagnosis that they would not have more children or were already unable to have children. Eight (50%) attributed this to their lack of choice in the decision, e.g.:

> I thought that my choice might have been taken away. That that was it….at the time we weren't thinking we'd have another one but I wanted it to be my choice (female, 35)

Five participants (two with children and three without; 20%) had a desire for children in the future and were distressed due to their perceived inability to have (more) children, e.g.:

> It's not going to kill me not to have anymore. But a little bit of me inside dies (female, 36)

Two women (8%) who had children and did not have plans for more stated that the loss of fertility had an impact on their perception of identity/femininity. One woman made reference to the ability to procreate as a unique role for women, e.g.:

> At a very base level, women's ability to procreate is part of our perceived attractiveness. Rightly or wrongly and it's totally illogical and it doesn't sit with the 21st century, but for most women my observation is you take away their capacity to procreate and they are less valuable (female, 47)

Theme 2: assumed infertility

The second theme relating to fertility perceptions, assumed infertility, was raised less frequently but with high emotiveness by participants. That is, there was a tendency for survivors who were uncertain about their fertility status to assume that they were infertile, with five out of the 15 respondents (33%) whose fertility status was uncertain at the time of the interview speaking as though they were definitely infertile, e.g.:

> Participant: I hadn't ruled it [having a biological child] out as such. But so I guess I have now. I guess that's the only real thing, it's that sort of 'okay…', because you know it's definitely…
> Interviewer: Is it definitely off the cards? Did you go through menopause as part of treatment?
> Participants: No well I, my periods were regular all

> through the chemo and…even during the last week when I was actually being treated I had one, but then I haven't had one since (female, 41)

Information and decision-making

Theme 3: lack of information regarding decision-making and fertility

This third theme was the most frequently and extensively raised concern by the participants, with seven issues being raised by them. First, ten participants (40%) felt insufficiently informed about the potential effect of treatment on their fertility before starting their treatment regime. In particular, eight participants (32%) felt that the *amount* of the information provided by their doctor was insufficient, with five participants (20%) stating that they did not recall having a conversation with anyone about fertility before the treatment began. Three participants (12%) felt that the *nature* of the explanation given about the potential impact of treatment was not adequate, e.g.:

> I think the doctors initially ask you, do you want to have any more children? And my answer was no. And so they didn't go on to give you any information about it. It wasn't until later on that it impacted on me…. the full extent of how my fertility was going to be affected (female, 36)

Of those that were informed about the potential impact, seven participants (28%) talked about being in 'survival mode' at diagnosis and were focused on treatment options that would maximise their chances of survival. Thus, the potential impact on their fertility seemed like a minor issue at a time when their survival was being threatened, e.g.:

> And I guess at that point you're really just focused on saving your life as opposed to what can happen in the future (female, 30)

Five participants (20%) stated that it was only once active treatment had started that there was a greater focus on quality of life and the full impact of living with potential infertility was realised, e.g.:

> It happened so fast as well. You don't really understand…you get diagnosed and bang you're in your surgery. Okay after surgery you can still have kids but then you're still sitting in your surgery bed being told you're having chemo and you don't realise well that's going to be the end of the ovaries (female, 38)

Four participants (16%) mentioned that they did not know if fertility resources existed, where they may be able to obtain them or who to ask for more information, e.g.:

> Knowing where to turn, that's been the difficulty (female, 30)

The lack of sufficient awareness about fertility loss induced a negative emotional reaction in some participants who were later surprised by the effect of the treatment on fertility, e.g.:

> I felt, not cheated, but a bit affronted that somebody had taken my fertility away and I didn't know about that (Female, 47)

Theme 4: patient recommendations

The final theme that was raised frequently and extensively in the current study related to the provision of recommendations to address the lack of information. Nine participants (five who had children and four who did not; 36%) suggested that they would have liked more information about the effect of treatment on fertility and their fertility options before the treatment started. Three of these participants had no plans for more children in the future. The participants made reference to receiving information that they could take home and consider, e.g.:

> Yes you need to be spoon fed a few things and if someone just says 'Okay if you want to talk about this, think about it and we'll talk about it at our next appointment'… it would sort of jog your memory to be sort of thinking about that and maybe have that discussion at home [with your partner] (male, aged 35)

Three participants (12%) suggested that the patients be provided with a list of treatment issues, including fertility, at the point of diagnosis to take home and consider.

The participants expressed a desire for information at the end of active treatment. Two participants (8%) made reference to feeling isolated from their cancer treatment team after the completion of active treatment. They subsequently encountered difficulty coping with potential infertility post-treatment as they did not know where to turn for support and information, e.g.:

> Their [the medical team's] job is really to fix you and I was fixed as far as they were concerned. I was in remission and that's all we really wanted in that point in time so they did their job and you …do feel like you're on your own to a point after that. Which I think is quite difficult to deal with as well (female, aged 30)

Two participants (8%) suggested that the patients be provided with a sheet of contacts, including appropriately trained counsellors, for follow-up if needed.

Other suggestions regarding information provision and support for patients regarding fertility issues included more discussion with doctors (two; 8%), more specialised support groups (two; 8%) and information in the form of a DVD (one; 4%) and seminars (one; 4%).

Discussion

The present study demonstrated that potential fertility loss was a significant concern for young cancer survivors for which they were poorly prepared. Of particular importance was the finding that people who already had children and/or who did not have plans for future children at diagnosis were also distressed by potential infertility. This may be because fertility related to the participants' concept of self. This potential explanation is supported by our finding that some respondents stated that the potential loss of fertility was distressing due to the perceived impact upon their sense of femininity, consistent with the theoretical notion that fertility, particularly for women, is central to sex role identification and identity [21, 22] and with empirical observations of cancer patients [23, 24]. This finding has important practice implications as patients who do not have plans for children in the future may not be considered as in need of support or information regarding the risks of fertility loss and may be less likely to be informed about potential infertility prior to treatment [18].

The present study has demonstrated that concerns regarding fertility relate to more than the desire to have children but also to one's identity as a woman (femininity) and the lack of control and choice regarding this outcome of cancer treatment. Fertility loss was an additional burden of cancer that became apparent and relevant after treatment was over and something that the study participants were not well prepared for. The magnitude of this burden might be added to by the fact that many participants assumed that they would become infertile, a finding consistent with the observation made by others who have shown that the young breast cancer survivors tend to overestimate their likelihood of chemotherapy-induced infertility and assume infertility post-treatment [3, 8]. This observation highlights the importance of appropriate information provision that includes accurate estimates of risk of fertility loss.

The present study demonstrated that the participants felt insufficiently informed regarding infertility and recognised that at the time of diagnosis, when most of the information provision takes place, fertility concerns may not be a high priority. The participants made decisions that would impact on their fertility during a time when fertility concerns were low and there was a delay between the onset of cancer diagnosis and treatment and the cognitive and emotional processing of potentially living with infertility.

Similarly to observations by others, the present study indicates that the perception of importance of fertility changes over time [8]. As a result, any information provision about fertility may not be sufficiently considered if presented at the time when fertility concerns were perceived as of low priority in comparison to cancer survival concerns. The present findings have significant clinical implications on information provision and support regarding fertility to cancer patients. This study highlights the importance of changing the way of how health care providers engage patients in fertility discussions. The discussion regarding fertility and cancer needs to not only deliver information that is appropriate in content, format and timing to the needs of the patient but also to engage the patient in order to facilitate decision-making and the desired degree of involvement in the process [25]. Evidence suggests that young patients prefer to be involved in decision-making and their adjustment is improved if they are involved in the process [26, 27]. Engaging patients in the discussion could potentially assist the provider in judging whether the timing of the discussion is appropriate and whether the issues need to be revisited in the future on more than one occasion. It is also important to recognise that the discussion is needed in circumstances where no change of plans is anticipated or desired (for example, where patients have already completed their family) as it is the engagement and involvement in decision-making and the sense of control which may be needed by the patient. As new resources regarding fertility are becoming available, it is important that emphasis is placed on how they can be best used to support the patients [28].

Similarly to patients in this study adopting the "survival mode", the providers may adopt a similar mode which may limit their engagement in discussion. Training providers in communication regarding fertility is needed in order to overcome the barriers to effective communication [29].

The participants in the present study offered a number of recommendations that could assist in the development of strategies for communication in this field, including provision of relevant information at multiple points in the course of the illness trajectory as well as provision of information regarding supports including other professional supports that may be available to them in this area. This is particularly important as evidence shows that cancer patients have reported difficulties communicating with their medical teams [30]. Involvement of other providers, for example, nurses and counsellors, in this process may indeed facilitate a multidisciplinary approach to the issues of fertility, assist the patient in dealing with this issue at the time of conflicting priorities and avert missed opportunities in dealing with this issue [31].

The primary limitation of the present study was the self-selection bias of the sample. Majority of the participants were married women, breast cancer survivors with a high level of education, and thus the results may have limited generalisability to other demographic groups that were less represented. In particular, only five men were included in the study, highlighting the need for studies focused specifically on the needs of men and fertility [32]. The study design was based on recalled information. Some participants had completed treatment for more than 2 years prior to the interview, and this may have affected their recollection of discussions with medical professionals. To avoid this, future studies should focus on assessing people within a specific time frame from cancer diagnosis. Finally, only one partner opted to take part in this study. Few studies have examined the concerns and needs of partners in relation to the patient's fertility, and it is unlikely that the partners of the cancer survivors are completely unaffected by fertility issues. The lack of partner participation may be due to a number of reasons such as the partner's desire to participate alone, an unwillingness to speak to a stranger or a time limitation. Information on the needs of partners and caregivers of cancer patients shows significant psychological needs [33]. It may be valuable for further research to focus on the partners of survivors and their concerns regarding fertility.

In conclusion, the findings of the present study indicate that young adult cancer survivors have significant concerns regarding the potential effect of treatment on their fertility for which they are poorly prepared. Fertility status may relate to more than the ability to have future children, and appropriately timed information and support services should be offered to all survivors regardless of parental status or plans for future children.

Conflicts of interest The authors do not have a financial relationship with the organisation that sponsored this research. The authors have full control of all primary data and agree to allow the journal to review the data if requested.

Appendix 1. Study questions

1. Tell me about your cancer journey.
2. Tell me about you and your family—partner, children, extended family (who do you see as your family), and how your cancer has impacted upon you and them.
3. What were your expectations regarding parenthood before and after cancer?
4. What are your perceptions of the impact of cancer and cancer treatment on fertility and sexuality?
5. What are your perceptions of the impact of cancer and cancer treatment on current and future parenthood?
6. Do you have concerns regarding fertility and sexuality? If so, can you describe these?
7. What impact have these issues (regarding fertility and sexuality) had on your quality of life?
8. What supports and resources relating to sexuality and fertility have assisted you in the past?
9. What supports and resources related to fertility and sexuality would you have liked to have access to? What about your partner (if applicable)?
10. Would you find it helpful to access resources about fertility, sexuality and parenthood online? Such as a Web-based interactive programme? Why/why not?
11. Do you have any other insights or comments about this area that you think is important for me to know? If so, what are they?

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