



The perceived impact of infertility on romantic relationships and singlehood among adult survivors of childhood cancer

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Abstract

Objective: To examine whether adult survivors of childhood cancer perceive a direct impact of potential/confirmed infertility on their romantic relationships/singlehood.

Methods: Open-ended qualitative phone interviews were conducted with 57 adult survivors of childhood cancer and analyzed through thematic content analysis until saturation was reached ($N = 30$).

Results: Interviews revealed three major themes: (1) impact on survivors, (2) impact on partners/romantic relationships, and (3) alternative routes to parenthood. An overarching theme related to (4) timing also emerged. In describing the impact on themselves, survivors shared subthemes of (1.1) becoming aware of infertility as potential late effect of childhood cancer treatment and (1.2) their emotional reactions (ie, worries/concerns, distress, guilt, no emotional reaction). The impact on partners/romantic relationships also included subthemes: (2.1) partner communication, (2.2) partner reactions, and (2.3) the journey of active family planning.

Conclusions: The perceived impact of potential/confirmed infertility on romantic relationships of adult survivors of childhood cancer varied across individuals and time. Its presence or absence depends on life circumstances (eg, marital status, life goals), and if present, negative effects were typically resolved over time by having a pregnancy. Other survivors found joy and comfort in step-children, considering adoption, or embracing a life without children. While more research is needed, findings indicate that discussions about infertility and fertility testing should be tailored to individual survivors and their needs, which may change over time. Timely referrals to reproductive specialists or adoption agencies are recommended for those who want children and have difficulties conceiving.

KEYWORDS

cancer, childhood cancer survivors, infertility, oncology, romantic relationships

1 | INTRODUCTION

Research among infertile, but otherwise healthy individuals indicated that unsuccessful attempts to conceive/sterility can cause distress and strain romantic relationships due to frustration, conflicts, and/or

break-ups.^{1,2} Similar findings have been reported among survivors of adult-onset cancer who wanted (additional) children after treatment,³⁻⁵ and the cancer experience may also alter whether survivors desire to have children.^{3,6} Although adult survivors of childhood cancer may experience comparable difficulties as they are frequently

faced with fertility problems (eg, reduced sperm count/ovarian reserve) or infertility/sterility in adulthood,⁷ little research has focused on this unique and diverse population.

Their uniqueness stems from circumstances at the time of diagnosis and treatment. In pediatric oncology, developmental stages and maturity of patients vary greatly, as does risk for infertility.⁷ Additionally, fertility preservation options vary by a child's age and sex, and remain experimental for young children.⁸⁻¹⁰ Families can also be overwhelmed by fertility-related and cancer-related information, or parents may choose not to share such information with their child.^{11,12} Due to the interplay of such factors, some survivors grow up knowing that they could be at-risk for infertility, whereas others may be surprised to learn about such risk in survivorship.^{11,13-16}

Such differences in risk awareness and/or fertility status may affect whether and how childhood cancer survivors engage in romantic relationships, but the available evidence is mostly anecdotal. For example, childhood cancer survivors reported thinking that others may not want to date them if they are infertile.^{17,18} Disclosing and communicating about (potential) infertility with romantic partners has been termed "difficult" or "challenging," and childhood cancer survivors may choose not to share this information.¹⁹⁻²¹ If disclosed, survivors report various partner reactions, ranging from positive responses to the dissolution of relationships.^{19,22} Overall, survivors have reported fertility-related concerns/worries,^{15,18,19,21,23,24} but whether such concerns directly affect the initiation, quality, or dissolution of romantic relationships among survivors is largely unknown.

Thus, this study examined whether adult survivors of childhood cancer experienced any (ie, positive or negative) impact of potential/confirmed infertility on their romantic relationships/singlehood at any time in their lives. Given the early state of the literature among childhood cancer survivors and lack of standardized measures, a qualitative approach was used. Survivors were interviewed in young adulthood, when family planning/childbearing constitute significant life choices.

2 | METHODS

2.1 | Participants and procedure

Data are from a follow-up assessment among childhood cancer survivors who previously participated in a study about psychosexual development.²⁵ Data for the initial study were collected from 2013 to 2015 when survivors were 20 to 40 years old, diagnosed at ages 5 to 18, and ≥ 5 years post-diagnosis. In 2016, all respondents ($N = 149$) were re-invited for this study. At that time, 28 survivors were lost to follow-up, and two had died. Thus, a maximum of 119 survivors received a mailed invitation letter, and 92 (77.3%) completed the online survey.²⁶ Upon completion, participants were invited to also complete a phone interview. Survivors who consented online were contacted ($n = 71/92$, 77.2%), and interviews were completed by 57 survivors. Interviews were conducted by trained research staff, audio-taped, and transcribed verbatim. Participants provided verbal consent over the phone, and all procedures were approved by our Institutional Review

Board (#IRB:16-00426). Interview questions and exemplary quotes are presented in the Supporting Information.

2.2 | Data analysis

Three authors conducted conventional thematic content analysis through an iterative process, and thus deriving themes/codes directly from the data.²⁷ First, authors immersed themselves in the interviews by individually reading the first 10 randomly selected transcripts. They identified preliminary codes based on recurring ideas/concepts. The authors then met to discuss all preliminary themes/codes, and consensus was reached for some, whereas others remained preliminary. Together, the authors developed a schema to preliminarily organize these themes/codes. Subsequently, a second group of 10 transcripts was read and coded by the three authors individually: The preliminary schema was used by each author to confirm and re-assess identified themes, and to add new themes/codes if necessary. Afterwards, the authors discussed these themes/codes again, and consensus was reached for final themes/codes. These were further organized into a framework to establish major/subthemes. Finally, a third group of 10 interviews was read, in which all identified themes were confirmed and no new themes emerged. Thus, saturation was reached in the first 20 interviews, confirmed by another 10, and no additional interviews were analyzed. The authors re-read each interview to confirm the developed framework.

As saturation was confirmed after 30 interviews, descriptive characteristics of the corresponding 30 survivors are represented in Table 1. Their socio-demographic/cancer-related factors did not differ from the full sample who participated online ($n = 62/92$; all $ps > .3$).

3 | RESULTS

Three major themes were identified: (1) impact on survivors, (2) impact on partners/romantic relationships, and (3) alternative routes to parenthood. Theme (1) and (2) contained subthemes and sub-categories (described below). Across all three themes, an overarching theme of (4) timing also emerged (Table 2; and see exemplary quotes for all categories in the Supporting Information).

3.1 | (1) Impact on survivors

In discussing the impact of potential/confirmed infertility on romantic relationships/singlehood, survivors often started their story by disclosing how they (1.1) became aware of infertility as (potential) late effect, and subsequent (1.2) emotional reactions. Such reactions included (1.2a) worries and concerns, (1.2b) distress, (1.2c), guilt, and (1.2d) no emotional reaction.

3.1.1 | (1.1) Awareness of (potential) infertility

Survivors indicated that they were made aware of infertility as potential consequence of treatment around the time of diagnosis. Some specified that this conversation occurred between them and their

TABLE 1 Descriptive characteristics of survivors (N = 30)

	M (SD), Range
Age	29.8 (4.4), 23-41
Age at diagnosis	11.8 (3.7), 5-18
Years since diagnosis	18.0 (4.4), 12-28
	n(%)
Diagnosis	
Solid tumor	9 (30.0%)
Lymphoma	8 (26.7%)
Leukemia	7 (23.3%)
Brain tumor	6 (20.0%)
Sex	
Female	20 (66.7%)
Male	10 (33.3%)
Race	
White	27 (90.0%)
Other	3 (10.0%)
Education	
Trade school or lower	12 (40.0%)
College degree	14 (46.7%)
Graduate degree	4 (13.3%)
Marital status	
Partnered ^a	24 (80.0%)
Single	6 (20.0%)
Biological parenthood	
Without children	16 (53.3%)
With children	14 (46.7%)

^aCommitted relationship or marriage.

parent(s) rather than with providers directly. Survivors indicated that they were unable to grasp the meaning of potential future infertility.

They didn't really give me specific details on telling me that I might be infertile [...]. I know they said something to my mom about maybe freezing some sperm cells, but I didn't. [...] at the time, I was so young. I didn't really understand what they were even talking about. (male solid tumor survivor, age 26, diagnosed age 13)

Other survivors noted that they did not become aware of potential infertility until survivorship. Throughout survivorship, they were told that infertility should not be an issue based on their treatment-indicated risk. Yet, providers' messages also included the caveat that

nobody could be certain until they tried to have children. Thus, many survivors were uncertain about whether their fertility was intact. One survivor stated she assumed her fertility was unharmed as no provider ever mentioned it.

Only one (male) survivor had cryopreserved semen before treatment, while another tried, but was azoospermic and thus assumed he was infertile ever since. Almost all survivors who mentioned fertility testing indicated that they had never been tested, but reported no aversion to it.

3.1.2 | (1.2) Emotional reactions

Survivors' emotional reactions toward potential/confirmed infertility varied and clustered into four subthemes (see also Supporting Information). Survivors reported subdued feelings of **worry/concern** (1.2a), labeling it as being *"in the back of my mind,"* whereas others frequently and intensely worried about their fertility. Those that were not currently concerned acknowledged that infertility could be problematic in the future. Moreover, survivors described concerns about finding a romantic partner and whether they would be scared away by potential/confirmed infertility.

Additionally, female survivors were concerned that their bodies may be unable to handle a pregnancy and carry a baby to term. Interestingly, the survivor who cryopreserved semen before treatment had frequently worried about his ability to sire a pregnancy. Concurrently, survivors were concerned about the health/well-being of potential offspring (eg, chromosomal abnormalities, genetic predisposition to cancer), creating doubts as to whether they should have children.

Survivors also reported experiencing **distress** (1.2b) due to potential/confirmed infertility. They described *"feeling down," "unhappy,"* and *"less of a person,"* while also acknowledging that these feelings would *"come and go in waves."* Overall, the time when survivors were uncertain about whether they could have children was described as *"stressful,"* and witnessing friends/siblings having babies aggravated feelings of sadness among survivors who were uncertain or reportedly infertile. Others noted that it was *"hard"* to grow up knowing they were infertile or coping with symptoms of menopause during adolescence. Yet, it also gave them time to adjust to being infertile.

Another emotional reaction described by survivors was **guilt** (1.2c). They felt guilty about not being able to "provide" a child for their partner and worried about the effects on them. Survivors indicated their partners never made them feel that way but described

TABLE 2 Impact of infertility on romantic relationships/singlehood

	Major Theme	Subtheme	Subcategory
(1)	Impact on survivors	(1.1) awareness of (potential) infertility (1.2) emotional reactions	(1.2a) worry/concern (1.2b) distress (1.2c) guilt (1.2d) no emotional reaction
(2)	Impact on partners/romantic relationships	(2.1) partner communication (2.2) partner reactions (2.3) journey of active family planning	
(3)	Alternative routes to parenthood		
(4)	Timing		

not wanting to be the reason for their partners to be without children. Interestingly, this was only mentioned by female survivors.

Nevertheless, some survivors indicated **no emotional reaction** (1.2d), reporting that they do not currently or have never worried about potential/confirmed infertility. This was due to not wanting children, believing that “*some things are just meant to be,*” or unplanned pregnancies that confirmed their intact fertility.

3.2 | (2) Impact on partners/romantic relationships

Survivors commented on the impact of potential/confirmed infertility on romantic relationships by describing their (2.1) communication with partners, (2.2) partners' reactions, and (2.3) journey of active family planning.

3.2.1 | (2.1) Partner communication

Survivors mentioned having had “*the talk*” with romantic partners about family planning and whether they want children like other couples. Yet, they highlighted the sincerity of such conversations due to the uncertainty surrounding their fertility. Survivors were either intentional about such conversations and only brought it up in serious relationships, or they were upfront about it from the start of any relationship. Other survivors noted they had not discussed fertility/family planning with any romantic partner because they had never been in a relationship, their relationships were not serious enough, or they were not at a point in their lives to consider family planning. Overall, survivors reported that conversations surrounding fertility were open and brought them closer to their partner.

“... we did talk about it. [...] The “dating talk” to figure out how compatible people are [...] How many kids do you want? What if you can't have kids? [...] Are you open to adoption? Are you open to fostering? Are you open to just not being parents and just, you know, traveling and doing all the not-parent stuff? And the husband that I chose was fine with all of those things, as was I. [...] I don't think that's unique to cancer survivors. I mean I feel like a lot of my friends who didn't have cancer, they all have the same conversations [...], but I think ours was a little more in-depth. Yeah, not having kids might really be a thing.” (female leukemia survivor, age 33, diagnosed age 7)

3.2.2 | (2.2) Partner reactions

Survivors who were in relationships spoke of their partners as being “*understanding,*” “*supportive,*” “*open,*” and “*accepting*” toward potential infertility. They reported that their partners adopted an attitude of “*figuring things out,*” “*taking things one step at a time,*” or they “*would be ok either way.*”

Negative partner reactions were only reported when referring to past relationships. This included pressure to have children from the partner and partner's family, or dissolving relationships due to unsuccessful pregnancy attempts (see Supporting Information).

3.2.3 | (2.3) Journey of active family planning

When describing the impact on romantic relationships, survivors elaborated most on their journey of trying to get pregnant. Survivors said it was difficult at the time and described this journey as “*hard,*” “*stressful,*” and/or “*very emotional.*” Such emotions intensified through months of unsuccessful attempts to conceive or miscarriages. Yet, it appeared that this stressful time was usually resolved by having a child. Other survivors described no such journey, either due to not trying yet, unplanned pregnancies, or deciding against having biological children.

“I think the only time for my husband and I that [cancer] was ever an issue is when I didn't get pregnant immediately. Obviously, I start thinking this is an infertility issue, because of having gone through chemo and radiation. I really think that's the only time I've ever communicated the most about it. Of course you know, he's reassuring me saying “I'm sure you're fine” and different things like that. But because [a pregnancy] wasn't happening at the time [...], I think that's the only time it has ever messed with our intimacy.” (female lymphoma survivor, age 33, diagnosed age 18)

Although all current partners/spouses were described as supportive, survivors also disclosed that partners were “*annoyed*” sometimes (eg, when “*obsessing*” about not getting pregnant). Furthermore, parts of the journey were experienced as more burdensome for survivors:

“I remember it being very stressful, very emotional. I remember sitting in the room at her initial consultation [with reproductive specialist] with all these pamphlets and a schedule of how often we had to come back, all the blood work, all of the medications [...]; and I remember, and I'm not generally an emotional person at all, I broke down. ‘Cause, again, I felt like it was all on my shoulders. And not because he made me feel that way, it was ‘man I've been through all of this [cancer treatment] and now I've got to go through all of this too.’” (female solid tumor survivor, age 35, diagnosed age 18)

Survivors were also told they should start a family early, which was experienced as difficult. While such remarks were made with particular ease by providers, survivors described the impact as burdensome. For example, being told to have children early, while not being financially stable or in a committed relationship, was experienced as problematic as they “*would not just want a kid with anyone.*” Similarly, such remarks “*hit hard,*” if survivors had just made certain life decisions (eg, entering college).

3.3 | (3) Consideration of alternative routes to parenthood

Overall, survivors described being happy with their situation which included having biological children, step-children, or no children. Yet, survivors who planned on or already had children, said it would be hard if they were without any children (biological or step-children).

Nevertheless, almost every survivor indicated that they and their partner had considered alternatives to biological parenthood. Most mentioned adoption and found relief in the thought that “there will always be adoption” in case they could not get pregnant. Others stated they always wanted to adopt regardless. Importantly, no survivor had followed through with adoption. One survivor reported that although her husband was supportive of adoption, he was relieved they got pregnant, as adoption would not have been satisfactory in hindsight.

Assisted reproductive technology (ART) was also mentioned as viable option, although for some survivors, adoption was the only alternative due to associated costs and the physical impact of going through ART procedures. Only one (male) survivor reported having tried ART with donor sperm, which was unsuccessful, while a (female) survivor had considered an egg donation, but eventually got pregnant. Surrogacy was mentioned by another survivor who also became pregnant herself.

3.4 | (4) Overarching theme of timing

Survivors' responses and the potential impact of infertility on romantic relationships/singlehood were dependent on time. Timing determined whether survivors ever perceived an impact. Thereby, components such as when/what they had been told about their fertility, when/whether they wanted children, or when/whether they would consider alternatives all played a vital role, along with other factors like relationship status or social environment (eg, postponing worries about infertility to the future when finding a partner, feeling sad when others have babies). In that sense, family planning in the face of potential/confirmed infertility may be seen as a developmental process, which includes negotiations with (potential) partners, trying (or deciding not) to have biological children, considering alternatives, and/or being appreciative of step-children or a life without children. Thus, having had cancer not only physically influenced survivors' fertility status, but also their perspectives/life goals.

“I don't plan on having children [...] if we get to the point where we want to have kids, we'll definitely adopt. [...] there is a chance that you're going to pass [cancer] on to your child and if [cancer] was as traumatic for [future children] as it was for me [...] I would hate myself if I had a child and they went through that too.”
(female leukemia survivor, age 32, diagnosed age 18)

“the first time, I remember [fertility] sort of being an issue was when my now husband, that I had been dating for a couple of years, and I would go back for my check-up and he would go with me. After two, three years of them realizing that we were still together, they sort of talked to us: [...]—hey there's a chance that you may not be able to have kids. We see this is a serious long-term relationship and that they wanted us to be aware of [potential infertility], I guess, so that we can discuss it to make sure that he was ok with that. So that's really the first time, I remember that that came into play. I was probably in my mid-twenties [...] and he was like

“Listen, you know, we're adults and they can't guarantee you whether you can or can't have kids. So we'll just take it as it comes.” (female leukemia survivor, age 41, diagnosed age 14)

4 | DISCUSSION

A perceived impact of potential/confirmed infertility on romantic relationships and singlehood of childhood cancer survivors varied greatly over time within and between survivors in the context of their life stage, marital status, partner perspectives, and parenthood goals. Some survivors noted that (potential) infertility led to worry, distress, and past partner conflicts, whereas others perceived positive or no effects. This study further indicated a lack of knowledge and misconceptions about fertility status and fertility testing. Collectively, findings highlight the importance of repeatedly discussing fertility and reproductive health with all childhood cancer survivors and allocating resources/referring to specialists based on individual needs.

Consistent with previous research among infertile, but otherwise healthy couples^{1,2} and adult-onset cancer survivors,³⁻⁵ our findings highlight the emotional strain of infertility/unsuccessful pregnancy attempts. However, some childhood cancer survivors in this study also reported positive or no consequences. For example, the cancer experience itself altered life goals/perspectives among some (eg, being happy without children), while the emotional and physical consequences of childhood cancer treatment also indirectly affected family planning (eg, not feeling physically and/or emotionally fit to have children, concerns about offspring health). Particularly, open communication with partners was described as a positive consequence of discussing infertility, while increasing their emotional closeness. Importantly, and in contrast to infertile but otherwise healthy couples, infertility was not confirmed for many survivors or worries were resolved by having a child, underlining the temporality of an impact of infertility on survivors' relationships. Survivors admitted that it would be distressing if they remained without children. Thus, it may be speculated that the emotional impact among survivors, who stay without children unwillingly, is comparable to infertile but otherwise healthy couples. Nevertheless, these healthy couples typically establish relationships and find out together about their fertility problems, while childhood cancer survivors must often navigate difficult conversations about having/wanting children early in their relationships.

Many survivors chose a wait-and-see approach, accepting their unknown/uncertain fertility status until they started trying to have a child. While there is merit to this attitude, this is mainly true for women. Female fertility testing options (eg, blood hormone levels, ultrasounds) do not always provide clear results but can be good indicators of reproductive potential. In men, semen analysis is gold standard for fertility testing and provides clearer results (although spontaneous recovery or declines of spermatogenesis may occur). Therefore, reports of fertility-related worries/anxiety in the absence of adequate testing and unplanned pregnancies underscore the importance of adequately counseling survivors about reproductive health.²⁸

Survivors, who had considered alternatives to biological parenthood, mentioned adoption as easy alternative. Yet, it remains

unknown whether survivors are aware of the lengthy and expensive process related to adoption. Overall, additional research is needed to better understand the experiences of aging survivors who remain without children (by choice or not), as attitudes toward family planning and life situations may change over time. Interestingly, guilt from potentially not “providing” a child to a partner was only expressed by female survivors. Thus, research examining sex differences in emotional reactions to (potential) infertility is warranted among cancer survivors, as men and women (in different cultural contexts) may experience infertility differently.^{2,29}

5 | STUDY LIMITATIONS

The representativeness of our sample, as in many qualitative studies, is questionable and replications in larger, more diverse samples (eg, regarding ethnicity, SES) are needed. Many survivors in this study were partnered and reported that having children resolved their fertility-related worries/concerns. Thus, survivors who unwillingly remain without children need to be considered. Additionally, no lesbian, gay, bisexual, transgender, or queer (LGBTQ) survivors were interviewed. Interestingly, LGBTQ survivors seem more open toward alternatives to biological parenthood and may be less emotionally affected by infertility.³⁰ Overall, quantitative research is needed to assess the magnitude of issues identified in this study and allow for identifying vulnerable (sub-)groups. However, reliable measures need to be developed first, and in the meantime, additional criteria to ensure rigor in qualitative studies are advised if feasible (eg, member checking, triangulation).^{27,31}

6 | CLINICAL IMPLICATIONS

Family planning is personal and may change over time. Therefore, health care providers should repeatedly address survivors' perspectives (ie, not assume every survivor wants children) and focus on potential misperceptions surrounding infertility and fertility testing. Offering fertility testing or referring survivors to reproductive specialists is indicated for those at treatment-indicated risk, those experiencing fertility problems, and/or those concerned/distressed about their fertility.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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