

Romantic Relationships and Physical Intimacy Among Survivors of Childhood Cancer

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Purpose: Childhood cancer survivors are at risk for impaired psychosocial functioning, but limited research has focused on psychosexual outcomes in young adulthood. This qualitative study examined the perceived impact of childhood cancer on adult survivors' romantic relationships and sexual/physical intimacy.

Methods: Phone interviews were completed with adult survivors of childhood cancer, exploring the impact of cancer on (1) romantic relationships and (2) sexual/physical intimacy. Verbatim transcripts were coded using thematic content analysis until saturation was confirmed ($n=40$).

Results: Survivors in this study ($n=40$) were 23–42 years old ($M=29.8$; 63% female) and 10–37 years postdiagnosis ($M=18.4$). Regarding romantic relationships, 60% of participants reported a negative impact, while 55% of participants reported positive effects; ~25% of participants reported no impact of childhood cancer on adult romantic relationships. Negative themes included fertility-related concerns, physical effects (e.g., self-consciousness), feeling emotionally guarded, and delayed dating. Positive themes were creating new perspectives, increased maturity, and stronger bonds with partners. Forty percent of survivors in this study perceived having fewer partners than peers. Regarding sexual/physical intimacy, 68% of participants reported a negative impact (themes: body image, fertility-related concerns, sexual/physical dysfunction), while 33% of participants reported no effects.

Conclusions: This study demonstrates both positive and negative effects of childhood cancer on adult survivors' romantic relationships, whereas effects on physical intimacy were predominantly negative. Further research is needed to inform effective psychosexual interventions, and health care providers should routinely address these topics in survivorship care.

Keywords: cancer, survivors, romantic relationships, physical intimacy, sexuality

Introduction

CHILDREN WITH CANCER often experience isolation from peers and reduced social engagement/activities, especially during the time of treatment.¹ Such social difficulties are potentially carried forward across the life span,²⁻⁴ given that studies report difficulties with romantic relationships² and sexual function^{5,6} among long-term survivors of childhood cancer. Previous research suggests that survivors, especially females, are less likely to get married or tend to get married at an older age.^{2,7,8} Yet, reasons for lower marriage rates remain largely unknown. Besides social difficulties, late effects of treatment such as fertility problems/infertility may hinder survivors' romantic relationships due to fear of or

actual rejection from partners.⁹⁻¹² Overall, relatively little is known about how the childhood cancer experience as a whole affects romantic relationships and sexual/physical intimacy among young adult survivors.

Sexual dysfunction has been indicated among one-third of childhood cancer survivors,^{11,13,14} and almost half of survivors rarely felt physically attractive or satisfied with their sex lives.³ Another study among female survivors found negative attitudes toward sexual pleasure and less frequent orgasms among survivors than female controls.¹⁵ Despite these findings, little has been done to address and treat sexual dysfunction among childhood cancer survivors.¹³ Pediatric subspecialists and primary care physicians rarely address sexual health and instead tend to focus on other concerns.¹⁶⁻¹⁹

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As a result, organizations such as the American Academy of Pediatrics have highlighted the importance of expanding the scope of reproductive and sexual health beyond pregnancy and sexually transmitted disease prevention, to also include fertility and sexual function counseling across at-risk populations.²⁰

Although most studies have found that adult survivors of childhood cancer have more sexual problems than peers,^{3,13,21} limited research has asked long-term male and female survivors with a variety of cancer diagnoses to reflect on their romantic relationships and physical intimacy in the context of their cancer experience. The majority of previous research on sexual dysfunction among childhood cancer survivors has been quantitative/survey-based, using surveys that are not specifically linking sexual issues and the cancer experience.^{3,6} More in-depth information is needed about these perceived late effects to educate health care providers on how to address psychosexual issues throughout care and to inform best practices for optimizing survivor well-being. Thus, the goals of this study were to qualitatively explore young adult survivor's perceptions of the (positive or negative) impact of childhood cancer (i.e., diagnosed at ≤ 18 years of age) on (1) romantic relationships and (2) physical intimacy/sexual function in young adulthood (i.e., 20–40 years of age).

Methods

Procedures

Following institutional review board approval, data were collected at a single institution from 2013 to 2015 for a larger study on psychosexual development among young adult survivors of childhood cancer.²² At the time of initial recruitment, participants were 20 to 40 years old, diagnosed between 5 and 18 years of age, ≥ 5 years postdiagnosis, and seen in clinic within the previous 2 years ($n = 149$). All respondents were reinvited by research assistants for a follow-up assessment in 2016 (including surveys and semistructured phone interviews), which provided data for this article. Interviews were conducted by multiple research staff trained in qualitative techniques, audiotaped, and transcribed verbatim by undergraduate students. Since initial enrollment ($n = 149$), two survivors died, and 28 were lost to follow-up. Thus, 119 survivors were mailed a letter inviting them to participate for this follow-up study, and 92 (77%) completed an online survey.²³ As part of the online survey (in which demographic information was self-reported and cancer-related information was derived from medical charts), participants were asked if they would also complete a semistructured phone interview, and 71 agreed (77%). Interviews were subsequently completed with 57 of the 71 survivors (80%). Saturation was reached after the first 30 transcripts were coded, which was confirmed by reviewing 10 additional transcripts. Socio-demographic/cancer-related characteristics of these 40 survivors are presented in Table 1.

Participants were asked the following questions with probes: (1) "Some people have said that cancer or their tumor has influenced their dating life and romantic relationships negatively, while others have said it influenced it positively or both. We would like to know how it has been for you." (*Probe if dating experience: For example, tell me more about how it has affected the number of romantic relationships? What about the*

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF THE STUDY SAMPLE ($N = 40$)

| | M (SD) | Range |
|------------------------------------|------------|-------|
| Age | 29.8 (4.8) | 23–42 |
| Age at diagnosis | 11.1 (3.2) | 5–17 |
| Years since diagnosis | 18.4 (5.9) | 10–37 |
| | n | % |
| Sex | | |
| Female | 25 | 62.5 |
| Male | 15 | 37.5 |
| Relationship status | | |
| Partnered | 34 | 85.0 |
| Single | 6 | 15.0 |
| Sexual orientation | | |
| Heterosexual | 38 | 95.0 |
| Bisexual | 1 | 0.025 |
| Unknown | 1 | 0.025 |
| Race | | |
| White | 36 | 90.0 |
| Other | 4 | 10.0 |
| Highest level of education | | |
| Graduate or professional degree | 7 | 17.5 |
| College | 22 | 55.0 |
| Technical or trade school | 2 | 5.0 |
| High school diploma or GED | 9 | 22.5 |
| Cancer diagnosis | | |
| Other solid tumors | 13 | 32.5 |
| Lymphoma | 12 | 30.0 |
| Leukemia | 11 | 27.5 |
| Brain tumor | 4 | 10.0 |
| Fertility | | |
| Been tested: fertile | 6 | 15.0 |
| Been tested: fertility impaired | 3 | 7.5 |
| Been tested: infertile | 2 | 5.0 |
| Fertility confirmed with pregnancy | 10 | 25.0 |
| Not been tested/status unknown | 19 | 47.5 |

GED, general educational development.

emotional closeness (or quality) of your relationships? If no dating experience: Why do you think that is? and (2) "Some survivors also tell us that cancer/their tumor has affected their physical intimacy or sex life, while others haven't had any problems. How has cancer/your tumor influenced your sex life and physical closeness, either positively or negatively?" (Probe if sexually experienced: What emotional factors have played a role in your sex life? How about physical factors? If no sexual experience: Why do you think that is? Is there anything else that comes to your mind when thinking about how cancer/your tumor might have influenced your sexuality?)

Analysis

Using an iterative process, three members of the research team (L.N., T.L.M., and K.G.L.) independently analyzed data through thematic content analysis using the constant comparison method.^{24–26} Transcripts were coded in the order that participants were interviewed, with transcripts from females coded first. Analysis began with reading 10 transcripts to gain an overview, followed by rereading to extract preliminary

themes and codes and develop a codebook. This procedure allowed the team to examine if themes and codes derived from the largest sample (i.e., females) held true or differed from males. Researchers kept notes of questions, potential comparisons, and leads for follow-up.²⁷ The researchers collectively reviewed the initial coding scheme, extracted quotes, and discussed reasoning for emerging themes after independent analysis of each group of transcripts. Discrepancies were resolved by group discussion and a final codebook of themes and categories was created. The codebook was applied to a new set of 10 transcribed interviews to determine fit with the existing categories. This process was repeated until saturation was reached, which was confirmed by reviewing 10 additional transcripts where no new themes emerged. Inter-rater reliability was good ($kappa = 0.87^{28}$).

Results

Participants reported various types of effects of cancer on their romantic relationships and sexual/physical intimacy, which were categorized as positive or negative, while some individuals also perceived no impact (Table 2). Negative effects on romantic relationships were reported by the majority of participants (*theme 1*), with positive effects reported by about half (*theme 2*). Notably, many survivors in this study noted both positive and negative effects of cancer on their romantic relationships, while a quarter stated that cancer had no impact at all on their romantic relationships (*theme 3*). Moreover, almost half of participants perceived they had fewer partners than peers (*theme 4*). The perceived impact on sexual/physical intimacy was predominantly negative (*theme 5*), including physical sequelae that directly affected sexual function, while many stated that cancer had no impact on their sex lives (*theme 6*).

(1) Negative effects of cancer on romantic relationships:

Over half of females and males noted cancer had negative effects on their romantic relationships due to the following: (1.1) fertility-related concerns, (1.2) physical effects, (1.3) feeling emotionally guarded, and (1.4) delayed dating (Table 2).

(1.1) Fertility-related concerns:

Participants noted that (potential) infertility negatively affected their romantic relationships, stating it raised issues with their partner or devastated them personally. Participants also noted that fertility concerns made them worry about their future, and that these issues may have interfered with past romantic relationships or ended relationships completely.

(1.2) Physical effects:

Survivors in this study reported that physical effects, often the result of treatment, made relationships difficult due to being self-conscious. Participants noted they were nervous to become romantically involved with another person due to the physical impact of treatment, including being postmenopausal or having scars from surgeries.

(1.3) Feeling emotionally guarded:

Survivors in this study reported feeling emotionally guarded and experiencing difficulty

opening up about their cancer experience to romantic partners. Specifically, participants reported taking longer to grow close to partners or being reticent to sharing their cancer experience.

(1.4) Delayed dating:

Participants often felt they initiated dating at a later time than their peers due to being treated/in the hospital during key developmental years, particularly as an adolescent or if they had to take a leave from school due to illness.

(2) Positive effects of cancer on romantic relationships:

Approximately half of females and males stated childhood cancer affected their romantic relationships in a positive way, including the following: (2.1) creating new perspectives, (2.2) increased maturity, and (2.3) stronger bonds with partners (Table 2).

(2.1) Creating new perspectives:

Survivors in this study noted that cancer made them grateful and/or appreciative of their partners or families. Participants also reported they did not worry about less important things, because they learned not to take life or their romantic partners for granted.

(2.2) Increased maturity:

Participants reported that having had childhood cancer made them more mature and caused them to grow up faster than peers, which was referenced as a positive. Specifically, survivors in this study said they had more adult conversations, whereas most of their friends did not, and that serious relationships held more meaning.

(2.3) Stronger bonds with partners:

Given the age range at diagnosis (5–18 years), the majority of survivors in this study were not dating their current partner at the time of treatment. Many of these young adults noted feeling more connected to their current partner when they shared their previous cancer experience. Some participants who were partnered while diagnosed stated that disclosing cancer or being with a partner while actively on treatment made them closer and ultimately strengthened their bond.

(3) No impact of cancer on romantic relationships:

Both females and males stated that cancer had no impact on their romantic relationships (Table 2).

(4) Perceived fewer partners than peers:

Another theme that emerged was that almost half of females and males perceived themselves as having fewer partners than their peers and/or having shorter relationships; there was no clear positive or negative impact noted, warranting categorizing this as its own theme. Specifically, some participants mentioned they were pickier than their peers with regard to dating (e.g., less inclined to engage in casual dating; Table 2).

(5) Negative impact on sexual/physical intimacy:

The majority of females and males stated that childhood cancer played a negative role in their sexual/physical intimacy due to (5.1) negative body image, (5.2) fertility-related concerns, and (5.3) physical sexual functioning (Table 3).

TABLE 2. NEGATIVE AND POSITIVE EFFECTS OF CANCER ON ROMANTIC RELATIONSHIPS

(1) Negative effects of cancer on romantic relationships (60%; n=24)

| (1.1) Fertility-related concerns | (1.2) Physical Insecurities | (1.3) Feeling emotionally guarded | (1.4) Delayed dating |
|---|--|---|---|
| <p>“I am infertile...sometimes I feel like it hinders especially in the past I was actually married before. I think a lot of it influenced why we got divorced...because he wanted kids and of course I love kids but I cannot have them.” (27-year-old-female, diagnosed with lymphoma at age 8)</p> | <p>“I’m considered postmenopausal, so it’s hard to be intimate with somebody that isn’t interested.” (27-year-old female, diagnosed with lymphoma at age 8)</p> | <p>“...maybe you don’t get as close as fast as some others.” (27-year-old female, diagnosed with leukemia at age 11)</p> | <p>“I was almost 18 so timing-wise, it took a year or two away from my ability to date... I was kind of behind things where all of my college friends had serious relationships at the end of high school and beginning of college. It was later before I had a serious relationship.” (36-year-old female, diagnosed with sarcoma at age 16)</p> |
| <p>“My only concern was fertility in the beginning [of starting to date], because I didn’t know whether we would be able to have kids or not.” (31-year-old female, diagnosed with lymphoma at age 10)</p> | <p>“I started having issues with erections. I went to a urologist, and they never got to the bottom of what the issue was. So I was always kind of self-conscious. I didn’t want to get into a relationship and then that be an issue. So it was always in the back of my mind to not get into a relationship or get romantically involved with anyone.” (35-year-old male, diagnosed with lymphoma at age 14)</p> | <p>“It’s affecting my dating life slightly negative, because it’s a big event...it’s something I’m reluctant to share with someone romantically.” (24-year-old male, diagnosed with sarcoma at age 10)</p> | <p>“I was diagnosed at 15, which is a time when you’re starting to explore having relationships. So when I was diagnosed in my high school years, it took that opportunity away from me since I was dealing with other things instead of the typical things that you would normally experience in high school.” (28-year-old female, diagnosed with lymphoma at age 15)</p> |
| <p>“It is...on the devastating side to know that you’re not able to bring somebody into the world yourself... you have that in the back of your head. Would somebody really be willing to be in a relationship with somebody that can’t do that?” (32-year-old female, diagnosed with germinoma at age 9)</p> | <p>“Having the scars, having all that and explaining all that with somebody new, it’s not any easy way to casually bring that up. So there’s anxiety and stress leading up to that conversation.” (27-year-old male, diagnosed with lymphoma at age 10)</p> | <p>“Well I guess in a negative way that this impacted me is just that I’ve felt that if whoever I’m interested in dating didn’t know about my history, that I was in some way lying to them or not really being truthful about who I am.” (27-year-old male, diagnosed with lymphoma at age 17)</p> | <p>“My tumor happened when I was 15 and 16 and so that was obviously probably a prime time where most people are starting to do adult dating and relationships, and so I was probably lagging behind a little bit.” (34-year-old male, diagnosed with sarcoma at age 15)</p> |
| <p>“In previous relationships [infertility] has been an issue...it was one of the factors that we discontinued our relationship.” (27-year-old-male, diagnosed with lymphoma at age 17)</p> | | | |

(2) Positive effects of cancer on romantic relationships (55%; n=22)

| (2.1) Creating new perspectives | (2.2) Increased maturity | (2.3) Stronger bonds with partners |
|---|---|---|
| <p>“I don’t take anything for granted. I always make decisions...with my wife or with my romantic life as if the cancer could come back tomorrow.” (42-year-old-male, diagnosed with leukemia at age 5)</p> | <p>“...we didn’t have those high school relationships and high school conversations but we also had more of adult conversations, like “Oh if I don’t survive this...” So I guess it’s just like a deeper level than just high school, you know boyfriend-girlfriend.” (27-year-old female, diagnosed with gastric cancer at age 14)</p> | <p>“Who I’ve been with now for a little over three years, he’s helped me see the positive side of all those things...it’s helped our relationship be even stronger.” (27-year-old female, diagnosed with sarcoma at age 12)</p> |

(continued)

TABLE 2. (CONTINUED)

(2) *Positive effects of cancer on romantic relationships (55%; n=22)*(2.1) *Creating new perspectives*

“It gives me more of an appreciation that I’m still able to be here.” (35-year-old-male, diagnosed with lymphoma at age 14)

(2.2) *Increased maturity*

“I went through that sort of psychological and physical trauma. [It] kind of forces you to grow up quicker, so frivolous things like random hook ups or spontaneous relationships don’t hold the same amount of importance for me as I think it would [for] a normal person. (27-year-old female, diagnosed with sarcoma at age 12)

(2.3) *Stronger bonds with partners*

“My wife when we were dating, I...told her my story. And that instantly made us closer and more connected, so you know in some ways [cancer] was negative, but in other ways it was very positive, because you know, how she reacted kind of reaffirmed that she was a person who I definitely wanted to be with.” (27-year-old male, diagnosed with lymphoma at age 17)

(3) *No impact of cancer on romantic relationships (25%; n=10)*

“I can’t really say it has had much of an effect on that area because I was so young and it was kind of before that time of my life.” (41-year-old female, diagnosed with leukemia at age 13)

(4) *Perceived fewer partners than peers (40%; n=16)*

- “I don’t really think it affected it either way...I...started dating my husband at 17, so we’ve been together for a long time. I mean basically the only one I’ve ever been with.” (31-year-old-female, diagnosed with lymphoma at age 10)
- “I haven’t dated many people and I married the third person I dated. I’ve always been very careful and not promiscuous and I don’t know if that has anything to do with being a cancer survivor or just being responsible...I think I was a little pickier than most people.” (33-year-old-female, diagnosed with leukemia at age 7)
- “I didn’t have a lot of the typical short relationships that other peers had. I had really serious relationships, I’ve only had two, and I married the last one.” (34-year-old-male, diagnosed with sarcoma at age 15)

(5.1) *Negative body image:*

Participants reported body image issues due to treatment effects such as scars and weight gain, which specifically affected their intimacy with romantic partners. Concerns about physical intimacy, including discomfort with being naked in front of a partner, were commonly noted even among those who were in committed relationships (e.g., married).

(5.2) *Fertility-related concerns:*

Fertility, particularly uncertainty about fertility, was reported to negatively affect intimacy and sex lives. Participants were concerned that their inability to have a biological child may scare off potential partners.

(5.3) *Physical/sexual functioning:*

Survivors in this study often noted physical and sexual functioning negatively impaired their physical intimacy. Fatigue, erectile dysfunction, or early-onset menopause were issues associated with lack of sexual interest and/or discomfort with physical intimacy.

(6) *No impact of cancer on physical intimacy:*

Many females and almost half of males stated that cancer had no impact on their physical intimacy/sex lives (Table 3).

were explored qualitatively in a large cohort of female and male young adult survivors of childhood cancer. Emergent themes demonstrate both negative and positive effects of childhood cancer on romantic relationships, whereas effects on sexual/physical intimacy were predominantly negative and a subset of survivors in this study reported no effects. These findings are consistent with prior research that shows effects on relationships may be negative,²⁹ positive,³⁰ or neutral,³¹ but that childhood cancer survivors are more likely to report sexual dysfunction than controls.^{13,21,32} In addition to expanding the literature regarding an overlooked aspect of survivorship, this study fills a gap by relating perceptions of romantic relationships and intimacy with the cancer experience, and by demonstrating that male and female childhood cancer survivors appear to have similar psychosexual concerns in adulthood.

Most participants reported several negative effects of cancer on their romantic relationships, including fertility-related concerns (e.g., feeling less desirable due to not being able to have biological children), physical effects, and feeling emotionally guarded, some of which have been reported in a recent survivorship research.^{10,12,29} Fertility-related distress and implications for romantic relationships have been reported among many male and female survivors^{29,33,34}; there is hope that fewer survivors will face these challenges in the future, given expanding access to fertility counseling and preservation before cancer treatment.³⁵⁻³⁷ Self-consciousness about scars, hair loss, weight gain, erectile dysfunction, and premature menopause were also frequently noted, which can negatively affect survivors’ sex lives. Although interventions (e.g., cognitive-behavioral) exist to address the physical impact of treatment, survivors do not routinely receive such

Discussion

This study is unique in that the effects of childhood cancer on both romantic relationships and sexual/physical intimacy

TABLE 3. NEGATIVE EFFECTS OF CANCER ON SEXUAL/PHYSICAL INTIMACY

(5) Negative impact on sexual/physical intimacy (68%; n=27)

| (5.1) Negative body image | (5.2) Fertility-related concerns | (5.3) Physical/sexual functioning |
|---|--|--|
| <p>“It’s always...a daily struggle honestly with me...my husband and I have been married for over a year, and we have been together for five years, and I still don’t like him to see me naked. ...I don’t know if that’s a normal woman thing, but...I don’t like to look at myself in the mirror naked. Why would I want somebody else to?” (27-year-old-female diagnosed with lymphoma at age 8)</p> | <p>“Just the fact of knowing that I cannot have kids would scare somebody off. That’s always played in the back of my head.” (32-year-old female, diagnosed with germinoma at age 9)</p> | <p>“Being postmenopausal...there’s never that interest there. I don’t know if it’s because of the postmenopausal, but it was just never really interesting to me...I would just rather lay in bed and sleep.” (27-year-old female, diagnosed with lymphoma at age 8)</p> |
| <p>“Because I had a lot of weight gain, and I was not excited about being undressed in front of anybody.” (36-year-old female, diagnosed with sarcoma at age 16)</p> | <p>“I didn’t think that I’d ever have a family and never be able to have kids of my own until this past year.” (29-year-old-male, diagnosed with leukemia at age 6)</p> | <p>“...Especially [pain] in my hips so that has kind of negatively influenced my sexual life, because I feel like an 87-year-old woman as opposed to a 25-year-old woman.” (25-year-old female diagnosed with leukemia at age 6)</p> |
| <p>“I just never felt comfortable...just, the scars, everything that it left physically behind just made me weary of who I opened up to.” (29-year-old-male, diagnosed with leukemia at age 6)</p> | | <p>“I’m going through the testosterone replacement to find what is working and what is not. So it’s kind of a rollercoaster ride right now, up and down, mentally and physically.” (35-year-old male, diagnosed with lymphoma at age 14)</p> |

(6) No impact of cancer on physical intimacy (33%; n=13)

| |
|--|
| <p>“I don’t know that it affected it positively or negatively...didn’t do anything to hurt...my sex life or romance at all.” (32-year-old female, diagnosed with leukemia at age 13)</p> |
| <p>“I can’t say that cancer has affected it either way. I mean it hasn’t affected me physically or mentally...that aspect of my life. I never gave it a thought.” (42-year-old male, diagnosed with leukemia at age 5)</p> |

care.³⁸ Previous research on achievement of psychosexual milestones has been somewhat inconsistent, with some studies showing similar patterns of dating as peers,³¹ and others showing delays in dating, masturbation, and sexual intercourse.³ The perception of having fewer partners than peers was commonly reported in our study, with a suggestion that these delays in dating are more pronounced among those diagnosed in adolescence rather than childhood. This finding highlights the need for further exploration of the effects of cancer on romantic relationships and intimacy in those diagnosed during this key developmental period, as illness and prolonged periods of hospitalization likely lead to “missing out” on many typical dating experiences during adolescence and young adulthood.

Although themes were similar across the two domains of romantic relationships and physical intimacy, future studies should explore why positive effects on romantic relationships do not necessarily translate to effects on physical intimacy. Our findings are consistent with previous studies that survivors experienced sexual dysfunction and perceived limitations on their sexual life due to scars, fertility concerns, or due

to being unable to express emotions.^{3,11,13} Females and males alike reported physical effects in our study, which is in contrast with previous research that shows females reported a negative change more often than males.³⁹ Our data highlight the importance of routine counseling for both female and male survivors, particularly since recent survivorship research has suggested there are associations between sexual dysfunction and overall well-being¹³ and that survivors report inadequate provider support in this area.¹¹ Recent guidelines published by the American Academy of Pediatrics offer recommendations for providers to initiate discussions about these topics in at-risk populations in a developmentally appropriate way.²⁰

In addition to negative effects of the cancer experience and consistent with previous research exploring post-traumatic growth after cancer,³⁰ many participants reported that the childhood cancer experience made them more mature and appreciative/thankful for their significant other, and strengthened their bond with a romantic partner. Nevertheless, research also shows accelerated psychological maturity among adolescents due to cancer having had a

negative impact on social functioning and difficulty connecting with peers.⁴⁰ This could be related to delayed dating, as identified in this study, but participants did not elaborate on the specific mechanisms of social interactions and delayed dating. Further research is needed to clarify whether such discrepancies in research findings are due to age, awareness in social functioning, or differences in social versus romantic connections.

Our findings should be considered within the context of several limitations. Participants were mostly white, female, heterosexual, partnered, and recruited from a single-treatment center potentially limiting generalizability. In addition, the questions specified “positively or negatively” to demonstrate the continuum of potential experiences and to underline that cancer may not only have negative implications in these areas, but this framing may have affected responses. Because data were already collected as part of a larger study, qualitative coding was conducted after study completion, preventing us from adjusting questions for validation or to expand on theory developed from participants’ experiences. Furthermore, completing quantitative analyses was not the goal of this qualitative study; rather, this study was meant to be exploratory in nature to address key knowledge gaps in this area. Despite these limitations, our findings can inform future research to better understand long-term, developmental outcomes in this population.

Our findings emphasize the need to more explicitly address the long-term impact of the childhood cancer experience on romantic relationships and intimacy. Furthermore, it is important to consider these implications starting at the time of diagnosis/treatment, particularly for adolescents who are potentially missing out on these important developmental milestones due to illness and frequent hospitalizations. Discussions should continue throughout survivorship in a systematic and structured manner, by designated providers of a multidisciplinary team (e.g., trained nurses, endocrinologists, mental health care providers, or other clinicians with expertise in sexual health).⁴¹ Given the potential complexities/conflicts between adolescents and their parents surrounding these sensitive topics (and ethical/legal considerations with regard to confidentiality), providers should openly address these topics with survivors without parents present, including sexuality, sexual function and health, fertility, and formation of romantic relationships, and document conversations in the medical record.²⁰

Counseling and interventions should focus on improving body image and sexual function to mitigate distress in the context of intimate relationships and reducing uncertainty with regard to fertility (i.e., addressing fertility status and reviewing options for fertility testing^{19,42}). Providers should normalize and initiate discussions about sex, while being mindful of diverse sexual orientations. They should also recognize that some survivors may have been too young at the time of diagnosis to have engaged in any discussions about intimacy/sexual function or fertility,²⁰ and that survivors may underreport sexual problems due to inexperience (i.e., not knowing what is “normal”). Using screening tools such as PROMIS may help survivors reflect on potential concerns and facilitate discussions around these sensitive topics.⁴³

In summary, this study demonstrates that survivors have a range of positive and negative perceptions of how cancer has influenced their romantic relationships, while some perceive

no impact. Many survivors perceive themselves as having fewer romantic partners than their peers. Primarily negative perceptions are reported with respect to how cancer affected their sexual/physical intimacy. More longitudinal research is needed to understand subgroups that may be at higher risk for psychosexual difficulties to inform interventions. In the interim, health care providers should engage in ongoing assessment and open discussion of psychosexual concerns with adolescent and young adult cancer survivors, as these challenges may evolve long into survivorship and are an important factor for the overall well-being and quality of life.

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