



# “What if I die and no one had ever romantically loved me?”: sexual well-being in a sample of YA cancer survivors

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## Abstract

**Purpose** Among young adult (YA) cancer survivors, sexual health is often exclusively focused on sexual functioning, or the completion of sexual tasks. However, it has become clear that there is another element of sexual health, sexual well-being—one’s subjective experience of sex (e.g., body image or sexual/romantic relationship satisfaction)—that may be just as impaired as sexual functioning. In this study, we sought to elucidate potential themes that YA cancer survivors experience that cross *both* sexual functioning and well-being, thus encouraging more comprehensive sexual health education among those diagnosed with cancer.

**Methods** Semi-structured interviews were conducted as part of a larger qualitative study. Three codes developed by a team of coders—Social Isolation: Dating and Sex, Self-Evaluative Emotion: Shame in Dating and Relationships, and Self-Evaluative Emotion: Shame in Body Image/Physical Ability Concerns—included both sexual functioning and sexual well-being, and therefore guided this analysis.

**Results** Our sample consisted of thirty-five YA cancer survivors who were predominately female (86%) and non-Latino White (77%). Four themes emerged: missing out/aging out, inability to please (potential) partners, body image concerns, and unmet needs for social support.

**Conclusion** While current research has identified sexual functioning as making up most of the sexual health education that cancer survivors receive, there is an interrelationship between sexual functioning and sexual well-being.

**Implications for Cancer Survivors** The clinical ramifications of the data are clear: more work must be done to address sexuality within both the couple *and* the individual survivor, and that work cannot be exclusively devoted to sexual functioning.

**Keywords** Sexual health · Sexual well-being · Sexuality · Body image · Interpersonal relationships · Unmet needs

## Introduction

Sexuality is an understudied area in individuals with chronic illnesses, despite serving as a key indicator of quality of life [1, 2]. Among cancer survivors, this may be due

to a “medicalization” of sexuality, with the majority of literature focusing on sexual functioning (i.e., bodily ability to move through the stages of the sexual response cycle), as treatment has been known to cause changes including loss of bodily sensations [3] and premature menopause [4] that may impact the ability to complete the sexual cycle. However, sexuality is best conceptualized as broader than just sexual function and should also include sexual well-being [1]. Whereas sexual functioning refers to one’s ability to complete the sexual response cycle, sexual well-being speaks to one’s subjective experience of sex (e.g., body image or sexual/romantic relationship satisfaction) [1].

Challenges to the development of sexual identity among cancer survivors may lead to difficulties with initiating romantic relationships and with maintaining such relationships [5]. This may be particularly salient

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among childhood cancer survivors (CCS), who are less likely to be in a romantic relationship or be married compared to healthy peers [6]. For those survivors facing the post-treatment world unpartnered, anticipated rejection from potential partners because of appearance changes post-treatment exemplifies difficulties with dating [7]. Additionally, unpartnered survivors face higher levels of dating anxiety compared to partnered survivors [8, 9], thus creating a barrier to relationship formation or maintenance.

Thus, understanding the relationship between functioning and sexual well-being among partnered and unpartnered survivors is highly relevant and would help identify targets of clinical intervention in discussions of cancer survivors' sexuality and sexual health. Issues with dating may influence sex, and issues with sex influence dating, creating this potentially bidirectional relationship between these two constructs [10]. Inequities within the cancer care experience, such as sexual and gender minoritized populations often citing discrimination from their healthcare providers, may speak to a lack of wholistic sexual education and knowledge disseminated to specific communities of young adult (YA; ages 18–39) survivors [11]. One study identified that 21% of LGBTQ cancer patients did not disclose their sexual orientation to any of their cancer care team, and identified that a strong predictor of disclosure to the care team was prior discussions of sexual health [12].

Given these structural and systemic correlates of partnerships in the general population, it is particularly imperative to expand the scope of research surrounding sexuality in cancer survivors to young adults. Sexuality is a highly relevant construct for this age group, as their developmental trajectory may lead to a new “sense of self” [9, 13]. This renewed sense of self provides the foundation for an emerging sexual identity and sexual responsiveness, which may affect the quality of (romantic and non-romantic) dyadic relationships [9, 14]. In one sample of young adult cancer survivors aged 18–45, nearly three-quarters of the women and two-fifths of the men reported having had less frequent sex since before cancer treatment [10]; however, more probing is required to identify whether such changes are due to sexual functioning, a loss of romantic relationships/partners, or both. Additionally, a significant amount of survivor relationship research has focused on survivors in long-term relationships [5], and has focused on survivors of cancer of the genitalia (e.g., testicular and breast), likely due to the focus on sexual functioning [15]. However, cancer disease and treatment of nearly any type can affect sexual well-being. In this analysis, we sought to better understand sexual functioning and well-being and the influences on each within a sample of YA cancer survivors.

## Methods

### Procedures for the parent study

YA cancer survivors were interviewed for a qualitative study intended to assess psychosocial functioning and identity. Survivors were recruited via survivorship organizations and targeted social media recruitment and self-identified interest in the study by completing an eligibility screening questionnaire. Individuals were considered eligible for the study if they (1) were 18–39 years old at the time of recruitment; (2) were diagnosed with cancer (any malignancy other than non-melanoma skin cancer only) between 13–39 years of age; (3) had completed active treatment for cancer between 2 and 5 years prior to study participation; and (4) were fluent in English. No participants refused participation after contact was made to schedule an interview.

The protocol and interview guide were approved by the Institutional Review Board at Hunter College. Due to the COVID-19 pandemic, all interviews were conducted via videoconferencing software, with only the participant and the interviewer in the videoconferencing room. There was no established relationship prior to study commencement. After consent was obtained, individual, semi-structured interviews (approximately 60–90 min in length) were conducted by the female doctoral candidate principal investigator (Zeba Ahmad, Ph.D.). Her training in qualitative interviewing was provided by Jennifer Ford, Ph.D. Participants were not given details about the interviewer.

The interview guide was adapted from prior interview guides used by our team, as well as the Autobiographical Memory Test [16, 17]. Participants were asked broad, open-ended questions about topics such as their future, changes in values or priorities due to cancer, and overall social functioning. Sex, sexuality, and romantic relationships were not necessarily probed unless self-introduced by the participants. These interviews were recorded for the purposes of analysis.

### Analysis

A team of 12 coders, as part of an educational and training experience, followed an inductive, open coding process, driven primarily by Braun and Clarke [18] where each coder independently read transcripts and then coders met as a group to create a codebook through consensus. Once three transcripts were coded in this way and the codebook was created, the remaining transcripts were coded by various pairs of coders, with a percent agreement of at least 80%, per established recommendations

[19]. All primary analyses were completed using Dedoose software [20].

For this analysis, three main codes were pulled from the codebook: (1) Social Isolation: Dating and Sex; (2) Self-Evaluative Emotion: Shame in Dating and Relationships, and (3) Self-Evaluative Emotion: Shame in Body Image/Physical Ability Concerns. All text that was coded for any of these three codes was reviewed for emergent subthemes by the first author via thematic analysis [21]. Once subthemes emerged, the authors met to ensure all agreement for the selected excerpts, as well as help with refining the text.

## Results

The final sample was comprised of 35 young adult (mean age = 31.69 years) cancer survivors (30 was the identified number of participants to achieve saturation; 5 further participants were recruited in an effort to diversify the sample). The majority of participants identified as female (88.6%) and White (85.7%). About half of participants (54.3%) were married or cohabitating, and the majority of identified as heterosexual (80%). The most common cancer diagnoses were lymphomas (31.4%) and breast cancer (25.7%). Full demographic data is shown in Table 1.

Eighty unique excerpts from 33 participants were found to have been coded for at least one of the four target codes in this analysis. Four key themes emerged when assessing these excerpts for constructs overlapping sexual functioning and sexual well-being: (1) missing out/aging out, (2) inability to please [potential] partners, (3) body image concerns, and (4) unmet needs for support. In order to support participant anonymity, non-cisgender and/or non-heterosexual participants are listed with “LGTBQ+” in their quote demographics.

### Missing out/aging out

Several participants noted a theme of missing out/aging out of key sexual and romantic developmental milestones. This feeling of missing or aging out extended to many facets of sexuality, including acts of sex, sexual relationships, and non-sexual romantic relationships. Participants who noted aspects of this commented on their own age as the key identifiable factor to demonstrate what they had missed out on. Issues related to both sexual functioning (e.g., ability to have sex) and sexual well-being (e.g., ability to have romantic relationships) were addressed.

One participant described how her sexual relationship with her husband had changed, demonstrating via comparisons with age:

**Table 1** Demographics

	<i>n</i> (%) <sup>a</sup>	
	<i>N</i> = 35	
Gender <sup>b</sup>		
Male	4 (11.4%)	
Female	31 (88.6%)	
Race <sup>c</sup>		
African American/Black	1 (2.9%)	
White	30 (85.7%)	
Native American	1 (2.9%)	
Asian American	2 (5.7%)	
Middle Eastern/Alaska Native	1 (2.9%)	
Not listed	1 (2.8%)	
Ethnicity		
Hispanic/Latino	4 (11.4%)	
Not Hispanic/Latino	31 (88.6%)	
Sexual orientation		
Straight/heterosexual	28 (80%)	
LGBTQ+	5 (14.4%)	
I don't know	1 (2.9%)	
I prefer not to answer	1 (2.9%)	
Cancer diagnosis		
Breast cancer	9 (25.7%)	
Lymphomas	11 (31.4%)	
Leukemia	4 (11.4%)	
Colorectal	1 (2.9%)	
CNS tumors	2 (5.7%)	
Kidney	2 (5.7%)	
Other	5 (14.3%)	
Thyroid	1 (2.9%)	
Relationship status		
Single, never married	12 (34.3%)	
Partnered	2 (5.7%)	
Married/cohabitating	19 (54.3%)	
Single, divorced	2 (5.7%)	
Highest level of education completed		
High school	1 (2.9%)	
Some college	7 (20.0%)	
College graduate	17 (48.6%)	
Post graduate level	10 (28.6%)	
Cancer stage		
Stage 0	1 (2.9%)	
Stage I	5 (14.3%)	
Stage II	12 (34.3%)	
Stage III	6 (17.1%)	
Stage IV	3 (8.6%)	
Don't know	8 (22.9%)	
	Mean (SD) <sup>a</sup>	Range <sup>a</sup>
Age	31.69 (5.624)	[18–39]

<sup>a</sup>Calculated from the total of non-missing data

<sup>b</sup>Includes both cisgender and transgender individuals

<sup>c</sup>Percentages may total greater than 100% due to multiple selections

6206J: So yeah, we often feel like we're 50 or 60 years old—well, 50, probably now it's better, but anyway. I think my parents probably have more sex than we do. [LAUGHS] I don't—but that's how I feel, basically, and I hope it gets solved soon and we can be more physically intimate. (35, female, invasive ductal carcinoma)

Another participant noted how taking a break from her sex life with her husband had caused her to miss out on that part of being a young adult:

4888V: So we're kinda actually taking a little break and—sexuality is such an important part of young adults... I mean we're in our prime and we want to have those experiences. And I feel like Tamoxifen is really holding me back. (36, female, invasive ductal carcinoma)

One participant noted the discrepancy between her age and what she has been able to experience sexually:

0691A: Like I feel like — when I'm sad about it, it feels like the best part of my sex life is gone. And that feels really sad because I'm, you know, I'll be 35 next month and I feel so young. (34, female, invasive ductal carcinoma)

However, many participants noted that it was not particularly *sex* they felt that they had missed/aged out of, but rather sexuality in general. One participant noted that such temporality in dating is due to societal pressure:

3163S: ...as a woman of my age and like the way that society views us as like aging, you know, getting closer and closer to 40 and like feeling like, well, life is over [laughs] once you're 40. As a single person, you know, like your worth just goes down. I don't believe any of that, but that's like the — that's what we're force fed from youth, and so just like being really confronted with that has been really difficult. (37, female, triple negative breast cancer)

Similarly, one younger participant spoke to feeling like he missed a romantic milestone that others might have:

5937R: I never, besides the girl who I was dating like pre-cancer, I didn't get my like, you know like crazy high school fling that I remember and tell my children about...I kind of missed out a lot when it comes to like being like you know 15, 16...it's kind of like that kind of window's gone now. (18, LGBTQ+ male, papillary thyroid carcinoma)

These missed milestones translated into future concerns for one participant, who noted a fear that she could die before getting to achieve specific romantic milestones:

1334M: And also, I—you know, when I had that feeling of like, oh my God, what if I die and no one had ever romantically loved me? I really did want to be involved with somebody... (35, LGBTQ+ female, Hodgkins Lymphoma)

However, this same participant noted a sense of acceptance with her situation, acknowledging:

1334M: Because right now, I'm just, I'm still just treading water. And that's okay. But like I'm not in a position to date anybody. And while that sucks because it feels like, you know, the clock is just going, it's a different clock than the baby clock, but that feeling like my youth is just being shirked from me, it's also okay because this is where I need to be while I need to be there. (35, LGBTQ+ female, Hodgkins Lymphoma)

Overall, participants reported missing/aging out both in terms of sexual functioning (e.g., holding off on sex due to medication) and sexual well-being (e.g., missing out on dating experiences). This was spoken about with primarily a negative connotation in regard to their current age, where their current age was the identifiable domain to demonstrate that they have “aged out” of certain experiences.

### Inability to please (potential) partners

A second theme that emerged from these transcripts was concerns about pleasing partners, and how these partners might react to such an inability. This concern extended to both sexual functioning (e.g., inability to perform certain sexual acts) and the intersection of sexual functioning and sexual well-being (e.g., concerns about not finding a partner due to this inability to perform certain sexual acts).

One participant reflected on her disappointment with how her husband was reacting to her sexual inabilities:

6206J: So literally, our honeymoon period was ruined. We didn't have sex for an entire year, actually, ... I remember my husband telling me, he said one thing that—one of the loss, the losses he had to go through was actually that he couldn't be very—he couldn't be very intimate, you know, with me. ... So yeah, that's the main problem with my husband right now in terms of relationship. Otherwise, he's perfect, yeah. (35, female, invasive ductal carcinoma)

Another participant noted a feeling of guilt for not being able to climax, particularly because she was having sex only to please him to begin with:

8143A: Orgasms are harder to reach. When I do reach them I feel like they're not as deep. You know, my libido is at -20. My friend, I guess he's a boyfriend, he, he's been so understanding through everything but

it's so frustrating because you know he wants to do it [*have sex*] so you want to do it but your body is like, "Nope you don't want to do it [*have sex*]." [laughs] "Nope, we don't want to do it [*have sex*]. Nope, stop. We don't want to do it [*have sex*]." And that's just, it's not fair to him, you know. It's just frustrating. (35, female, HER-2 positive breast cancer)

However, one participant noted positive partner reactions, particularly in the context of dating:

6513K: I think at first the big fear was relationships. I was like, I can't open my mouth as wide as some people. I have dry mouth...I would try, I would try stuff. Right, like I would say, "Oh can we try this?" Or like whatever or if I'm just like, "I can't do that," like they [*potential partners*] were fine with it and that was a big fear. (30, LGBTQ+ female, squamous cell carcinoma of the tongue)

This participant went on to note a similar theme of acceptance to what was demonstrated in the missing out/aging out category:

6513K: I was like no one's going to want someone who can't like go down on them if it's a woman or like give them a blowjob if it's a guy. I was like no one's going to want that you know but they've [*potential partners*] all been like fine. So I'm like okay so clearly these people who are not my long term partners have been fine so if anyone's not fine then they're not meant to be the long term person and that's that. So that's how I reconciled that. (30, LGBTQ+ female, squamous cell carcinoma of the tongue)

Overall, participants noted both positive and negative partner reactions to their sexual inabilities. While some participants found such inabilities had a negative effect on their sexual lives, others seemed to find liberation in discovering that the fears they had about dating may have been unfounded.

### Body image concerns

Partner reactions were a similar theme whenever body image came up in these excerpts. The intersection of sexual functioning and sexual well-being was once again at the forefront of these excerpts, with participants noting times they had to revoke consent from partners at the start of sexual encounters due to negative comments about their post-cancer bodies, concerns about comments potential future partners might make, and differences between one's own view of their body and the way others viewed it.

One participant recounted a time when she had to revoke consent due to a negative reaction to her scar:

2050H: ...with [Name 3], again, it [*partner's reaction*] was unwanted and he saw it and he was like, oh—like I saw his face and he's just like, oh, I didn't know it was that big. And I just saw his reaction and [pause]—just being in that place where I wasn't able to do anything to tell him—like I told him no and I wanted my shirt back and it was just like it's not like I can fight you because I'm in like 20 out of 10 pain and I just had surgery two weeks ago. (37, female, clear cell renal cell carcinoma)

The same participant reflected on how this reaction makes her wary of future relationships:

2050H: And just, okay, is the, is the future person gonna react the same way, oh, I didn't know it was that big, oh, you know—his—I mean—and the doctor told me last, at my last appointment like I mean, part of it's healing, part of it's healing. I mean it's a healthy scar, there's nothing wrong with it. It's just part of it's just not gonna heal correctly. Like it's just how it is. (37, female, clear cell renal cell carcinoma)

Another participant recounted how a partner had not been sufficiently attuned to scarring from cancer treatment:

3163S: And it was like, you know, the first time that I was intimate with somebody since my ex-boyfriend and since having cancer and since Covid. And he did point out some of my scars and was stupidly — like there's one right here that you, you can see it on my chest and he was like, "What's that from?" And — because that's not an obvious breast cancer scar. So I had to explain that that was where my port was, you know, like that's what that is. He's like, "Oh, I thought you had like gotten stabbed or something." (37, female, triple negative breast cancer)

However, one participant recounted how a partner's non-chalance about his appearance gave him optimism:

5577S: Yeah, I mean, when we, when we went on our first date, I was still bald and had no eyebrows, so there, there was really no concern that, that she wouldn't like me for, for me.

Q: That's great. How does that make you feel about the relationship?

5577S: It makes me feel...like she's gonna stick around. (26, male, testicular cancer)

There were also a significant number of excerpts focused on the dichotomization of one's own body image compared to how others may see their body. For example, one participant described how she set a boundary between the medicalization of her body and her partner in order to "reclaim" intimacy:

7530L: And so something that I stopped doing was, like, I stopped communicating things about my body or, like, my medical—just, like, medical day to day stuff that, like, he [*participant's husband*] didn't need to know. Like, I stopped flushing my line in front of him [*participant's husband*] as, like, “I don't need him to see me like a patient.” So it just a way of, like, sort of like getting privacy again around parts of my body... (31, *female, T-cell acute lymphoblastic lymphoma*)

Another participant took this a step further, acknowledging how she felt differently about her own self-image and how others see her body:

0691A: I feel like good in a bra. I feel like my plastic surgeon did a good job. I look good in a bathing suit. But it's weird. Like taking that off and being intimate is, is — I, I want to hide. (34, *female, invasive ductal carcinoma*)

Overall, the participants who spoke to themes of body image all spoke to how partners reacted (i.e., negatively, or not at all) and how they felt differently with themselves as compared to with a partner, reflecting that partners may play a key role in how body image is considered. Additionally, these excerpts are clearly of those who are in, or recounting times they were in, married/committed relationships. One participant (7530L) recounted setting up the boundary between partner and caretaker, reclaiming her bodily autonomy and ensuring that her partner remained her romantic and sexual partner, rather than a caretaker (as has been established in previous research) [22].

### Unmet needs for support

A final theme of unmet needs for support surrounding sexual well-being, not just sexual functioning, was uncovered. This theme illustrated the idea that medical professionals are more focused on surviving the cancer experience than quality of life.

One participant recounted:

2133M: I mean, one of the most difficult things, I think, that is an aftereffect of cancer that is not touched and that has a lot to do with relationships is sex. You're greatly affected by the—either the ability to have, the dealing with the pain, dealing with, like, no drive because, like, my hormones are so low. That is not things that they talked to us about, and, like, currently, like—I mean, currently and for a while now, it has taken a big strain on my marriage life, frankly, and yeah, like I said, they don't touch it. (36, *female, Hodgkins Lymphoma*)

This participant also noted the lack of other side effects that go unmentioned by medical doctors:

2133M: They [*doctors*] don't tell you about this. That, like—they [*doctors*] tell you, “Oh, take the medicine, this medicine is going to help you, like, take this medicine and get better.” And then, like, after, you're like, “Okay, now I'm left with, like, a sexless marriage, my teeth are all messed up from the chemo, and I have to have them all replaced.” They [*doctors*] don't tell you that, they don't talk to you about that, you know? (36, *female, Hodgkins Lymphoma*)

Thus, this participant felt that their doctor was more focused on survivability than components of sexual well-being and body image.

### Discussion

Of the extant literature on YA cancer survivors, sexual health research is often focused on sexual functioning as an obstacle to reproduction [23]. Of the extant research, much is quantitative, thus failing to center around the voices of the YA survivors. Our key themes of “missing out/aging out,” inability to please (potential) partners, body image, and unmet needs for support provide novel data to assess the interplay between sexual well-being and functioning. Additionally, most of these constructs surround one central theme: social comparison.

Social comparison theory is often used to assess the context within which young adults navigate the world. It states that self-evaluation is often used to obtain information about the self, as compared to others; self-enhancement, meanwhile, is often a protective factor that is used to enhance feelings about the self and maintain positivity toward the self [24]. In this study, we see this self-evaluation when participants note their sexual abilities and/or body image compared to others (e.g., “I think my parents probably have more sex than we do”; “no one's going to want someone who can't like go down on them if it's a woman or like give them a blowjob if it's a guy”). Self-enhancement is demonstrated in those who have begun to accept their newfound relationship with sex and sexuality (e.g., “like the way that society views us as like aging... I don't believe any of that, but that's like the — that's what we're force fed from youth”; “And while that sucks because it feels like, you know, the clock is just going...it's also okay because this is where I need to be while I need to be there”). These two constructs of social comparison theory likely provide a window through which we can interpret this interplay between sexual functioning and sexual well-being.

Previous research has identified a need to assess dating and relationships in childhood cancer survivors from the

perspective of “missing out” on key milestones, particularly dating and intimacy [25]. Although this was not an a priori research area of focus, it was elicited by open-ended questions about post-treatment life among survivors. This self-evaluative construct was identified by participants stating they were “aging” or “missing out.” Previous research among cancer survivors has often pulled out a theme of “dying out” or “loss” of a sexual life [26, 27]. While our results are similar, there was a clear differentiation of “missing out”—that is, most of our participants spoke of sexuality as temporarily missing, but feeling as though this was not permanent. This may speak to the younger demographic of our sample—it is possible that older survivors may be more inclined to view sexuality as “lost” with age, with a permanency that our sample did not demonstrate. Additionally, many participants commented on their chronological age, feeling as though they were aging out of a sexual prime, despite being young (e.g., “we often feel like we’re 50 or 60”; “sexuality is such an important part of young adults... Tamoxifen is really holding me back”). Previous research on YA survivors of childhood cancer has noted a similar theme, identifying that these survivors often note that they face a dichotomization of feeling both like they were growing up faster than their healthy peers, while also feeling behind their peers as they miss out on key developmental events [28]. In this sample, “missing out” also connoted feelings of social isolation, induced by the assumption that same-age peers were having different experience and had expectations for body image and sexual functioning. Thus, for these participants, self-evaluation was used as a means to facilitate both the view that their sexuality was temporarily lacking, as well as noting a discrepancy between their life and the lives of others.

We see this same theme reflected in those who spoke about dating, or previously seeking romantic relationships. These participants spoke about clocks ticking and concerns that they might die before ever having found romance. However, within this sample, we also see a participant note acceptance about not being ready to date. This is a theme that has been previously reflected in research on women with cancer, who *chose* to temporarily pause their sexual lives [29]. This sense of choice may lead to acceptance—by choosing to put dating or sexuality on pause, survivors might be able to gain a sense of acceptance of their own trajectory and raise a barrier against the feelings of aging or missing out on perceived norms. In choosing such a trajectory, we also see an example of self-enhancement; participants are readily able to accept their situation as a means of ensuring that they do not feel that they have lost a significant part of their life.

However, there is a similar theme of acceptance that becomes delineated between those in relationships and those not in regard to sexual abilities. Previous research has

identified a feeling of guilt or a sexual “need to provide” for those who have had cancer [27, 30]. This is a clear theme among these participants when describing relationships, who identified using keywords such as “ruined,” “loss,” and “frustrated” in regard to their sexual relationships. However, for one participant, it became less of a negative emotion about guilt and more about her partner’s reaction to that loss (“that’s the main problem with my husband right now”), signifying that for some participants, there may be an underlying dissatisfaction with the relationship. One participant stated acceptance with their sexual situation; interestingly, this is a participant who is clearly without a committed relationship. Thus, we once again identify a theme of those without a committed relationship having an ability to navigate their sexual well-being and dating life in a way that those tethered to others are identifying negative effects. It may be that partners provide an easy way to facilitate and promote social comparison, thus making it easier for cancer survivors to identify areas in which they feel that they are lacking, compared to others.

Similarly, when participants spoke of partner reactions to body image during sex, they spoke of negative experiences reengaging in partnered sexual activity. In that way, it seems as though those who are married/in committed relationships may not have the same negative partner reactions during sex. Previous research has identified a similar theme about how a past of negative partner reactions creates a fear of future partner reactions [31]. This begs the question for future research as to whether those who are married/in committed relationships are less likely to receive negative reactions from their partners during sex. For contrast, when we step away from the direct action of sex and focus on relationships as a whole, the excerpts were much more optimistic in tone, focused on positive partner reactions to body changes and reclaiming the boundary of partner vs. caregiver. Whereas previous research has described women attending medical appointments alone in order to avoid upsetting their partners [32], in our study, this was seen more as a sign of independence and bodily autonomy.

There was a recurring theme in this sample of a focus on individuality, rather than partners. For instance, previous research surrounding sexually missing out has discerned, in regard to sex, a focus on the couple, or of a “shared loss” [27, 33]; these results, however, have a significant focus on the self instead of on the partner (e.g., “it feels like the best part of my sex life is gone” and “that’s how I feel, basically, and I hope it gets solved soon”). These data are also novel in that they demonstrate a difference between how one perceives themselves and concerns about how others would see them, especially regarding body image. Previous research has identified that cancer patients and survivors, particularly women, have a very dichotomized take on their relationship with their body: women who did not like their

body, and women who were afraid to show their body to partners [29]. These data present a merging of these two concepts, wherein some women *like* the way that they look *until* they are in an intimate situation (as demonstrated by the final body image excerpt). This may reflect a lack of counseling surrounding sexuality changes and intimacy issues for cancer survivors, as we know that very little outside of sexual functioning is often spoken about to survivors as potential side effects [32, 34].

Indeed, that lack of counseling is reflected in the final theme of unmet needs for support, which illustrated a lack of medical advice surrounding sexual functioning and sexual well-being. Previous research has identified a focus on sexual functioning [32, 34]—thus placing those in sexual relationships with more knowledge than those who are not, and completely eliminating discussions about outside of the realm of sexual functioning. This focus is likely due to an assumption that doctors are there to help their patients survive their disease, nothing more [32, 34]. However, there are times where sexual functioning may not even be mentioned [35], prompting this theme of sexual health as an unmet need. This is clearly reflected by the participant who spoke to this matter, who spoke about both a lack of discussion on sexual functioning *and* sexual well-being. To that end, these data prompt a discussion about the medicalization of cancer, and whether patients feel that they can bring their questions that do not focus on survivability to the table. Since YAs are likely to still be in the process of developing their identity as sexual beings, they may be less equipped than older adults to identify and ask healthcare providers for what they need support with. Comfort, normalization, and open communication about sexual well-being is therefore especially necessary to this age group.

Regardless of age group, however, it is important to note that unmet needs may be exacerbated in certain subpopulations of cancer patients and survivors. LGBTQ+ participants may be less inclined or able to discuss their sexual health needs with their care team, as in order to do so, they must disclose a significant part of their identity—and there could be concerns that such disclosure might impact the care they receive [36]. Similarly, research has identified that racial and ethnic minorities often endorse more unmet needs than non-Hispanic White participants; it is possible that, even with the limited sexual information that our participants endorsed, non-White and/or Hispanic cancer survivors may be provided even less information [37].

It would be also be remiss not to mention that the data being reported on in this study are being read through the lens of heteronormativity and monogamy. Future research should identify ways in which cancer survivors who identify as LGBTQ+ and/or engage in non-monogamy navigate their sexual lives. Health care professionals, when providing sexual health information, may assume that a patient

identifies as heterosexual; one study found that only 25% of providers inquire about a cancer patient's sexual orientation [38]. It would be important to assess how differences in LGBTQ+ individuals and within queer relationships impact the relationship between sexual well-being and sexual functioning.

As such, there are a few noteworthy limitations to this study. The study sample of cancer survivors was heterogeneous with respect to biological sex, type of cancer, sexual orientation, and religion. Given this, it is possible that interest in sexual activity—or discussing sexual activity—may differ by type of cancer (e.g., cancers affecting genitalia), sexual orientation (e.g., non-penetrative sex), and/or religion (e.g., concerns surrounding sex before marriage). Notably, given our small number of participants, subgroup analyses would have been impossible. Future research should seek to assess these data with subpopulations of YA cancer survivors in order to assess the intersection of sexual functioning and sexual well-being among subpopulations, particularly sexual orientation. Second, as noted earlier, questions surrounding sexual activities were only asked of those who self-reported sexual activities during the interview; therefore, the data presented likely do not gather all thoughts about sexuality within this population. Future work should assess unmet needs for support in the context of clinical care surrounding sexual health. Additionally, relationship functioning and status were not necessarily probed. Future research should assess whether these distinctions in themes established in this study track with specific relationship statuses.

In sum, these data provide insights on the interaction between sexual functioning and sexual well-being among YA survivors of cancer, particularly with regard to missing out/aging out, inability to please (potential) partners, body image, and unmet needs for support. Given these findings, it is apparent that there need to be renewed calls for both individual and relationship counseling on sexuality, wherein survivors can discuss both issues that they may face on their own, as well as in the context of a partnered relationship. Such counseling, particularly for the survivor, might focus on ensuring that social comparisons do not serve to further hinder the ability to participate or be interested in sexual activity. Healthcare providers may initiate such counseling by engaging in the PLISSIT model, ensuring that they ask an open-ended question about sexuality and sex with their cancer survivors and patients at every appointment, allowing the participant to know that the provider is open to answering questions surrounding sexual health [39]. Similarly, it would behoove local governments to adapt sexual education materials tailored to those with or survivors of chronic illness, who may not be as readily able to obtain such information.

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**Data Availability** Data is not publicly available, as this would risk participant anonymity.

## Declarations

**Ethics approval** This study was performed in like with the principles of the Declaration of Helsinki. Approval was granted by the Institutional Review Board at Hunter College (protocol #2020-0869).

**Consent to participate** Informed consent was obtained from all individual participants included in the study.

**Conflict of interest** The authors declare no competing interests.

## References

- Verschuren JEA, Enzlin P, Dijkstra PU, Geertzen JHB, Dekker R. Chronic disease and sexuality: a generic conceptual framework. *J Sex Res Taylor & Francis, Ltd.*; 2010;47:153–70.
- Clayton A, Ramamurthy S. The impact of physical illness on sexual dysfunction. *Adv Psychosom Med.* 2008;29:70–88.
- Davies CC, Brockopp D, Moe K, Wheeler P, Abner J, Lengerich A. Exploring the lived experience of women immediately following mastectomy: a phenomenological study. *Cancer Nurs.* 2017;40:361–8.
- Nasiri A, Taleghani F, Irajpour A. Men's sexual issues after breast cancer in their wives: a qualitative study. *Cancer Nurs.* 2012;35:236–44.
- Shaw L-K, Sherman KA, Fitness J, Breast Cancer Network Australia. Women's experiences of dating after breast cancer. *J Psychosoc Oncol.* 2016;34:318–35.
- Wengenroth L, Rueegg CS, Michel G, Essig S, Ammann RA, Bergstraesser E, et al. Life partnerships in childhood cancer survivors, their siblings, and the general population. *Pediatr Blood Cancer.* 2014;61:538–45.
- Shaw L-K, Sherman K, Fitness J. Dating concerns among women with breast cancer or with genetic breast cancer susceptibility: a review and meta-synthesis. *Health Psychol Rev.* 2015;9:491–505.
- Shaw L-K, Sherman KA, Fitness J, Elder E, Australia BCN. Factors associated with romantic relationship formation difficulties in women with breast cancer. *Psychooncology.* 2018;27:1270–6.
- Carpentier MY, Fortenberry JD. Romantic and sexual relationships, body image, and fertility in adolescent and young adult testicular cancer survivors: a review of the literature. *J Adolesc Health.* 2010;47:115–25.
- Geue K, Schmidt R, Sender A, Sauter S, Friedrich M. Sexuality and romantic relationships in young adult cancer survivors: satisfaction and supportive care needs. *Psychooncology.* 2015;24:1368–76.
- Diamant AL, Schuster MA, Lever J. Receipt of preventive health care services by lesbians. *Am J Prev Med.* 2000;19:141–8.
- Kamen CS, Smith-Stoner M, Heckler CE, Flannery M, Margolies L. Social support, self-rated health, and lesbian, gay, bisexual, and transgender identity disclosure to cancer care providers. *Oncol Nurs Forum Oncol Nur Soc.* 2015;42:44–51.
- Bancroft J. Sexual development in childhood. Indiana University Press; 2003.
- Arnett JJ. Emerging adulthood: a theory of development from the late teens through the twenties. *Am Psychol.* 2000;55:469–80.
- Diamantopoulou M, Pitis A, Raftopoulos P, Tzavella F. The impact of oncological diseases on sexual behavior and psychosocial attitudes of young and adult patients: a systematic review. *Int J Caring Sci.* 2019;12:1175–87.
- Szpunar KK, Spreng RN, Schacter DL. Toward a taxonomy of future thinking. In: Michaelian K, Klein SB, Szpunar KK, editors. *Seeing the future: theoretical perspectives on future-oriented mental time travel* [Internet]. Oxford University Press; 2016. <https://doi.org/10.1093/acprof:oso/9780190241537.003.0002>.
- Hotchkiss HE, Ahmad ZN, Ford JS. Cancer–peer connection in the context of adolescent and young adult cancer: A qualitative exploration. *Journal of Adolescent and Young Adult Oncology.* 2023;12(1):83–92. <https://doi.org/10.1089/jayao.2021.0170>.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol Routledge.* 2006;3:77–101.
- O'Connor C, Joffe H. Intercoder reliability in qualitative research: debates and practical guidelines. *Int J Qual Methods.* SAGE Publications Inc; 2020;19:1609406919899220.
- Dedoose Version 9.0.17, web application for managing, analyzing, and presenting qualitative and mixed method research data [Internet]. Los Angeles, CA: SocioCultural Research Consultants, LLC; 2021. [www.dedoose.com](http://www.dedoose.com)
- Braun V, Clarke V. Thematic analysis: a practical guide. London: SAGE Publications Ltd; 2021.
- Reis N, Beji NK, Coskun A. Quality of life and sexual functioning in gynecological cancer patients: results from quantitative and qualitative data. *Eur J Oncol Nurs.* 2010;14:137–46.
- Murphy D, Klosky JL, Termuhlen A, Sawczyn KK, Quinn GP. The need for reproductive and sexual health discussions with adolescent and young adult cancer patients. *Contraception.* 2013;88:215–20.
- Wood JV. Theory and research concerning social comparisons of personal attributes. *Psychol Bull US: Am Psychol Assoc.* 1989;106:231–48.
- Nahata L, Morgan TL, Lipak KG, Olshefski RS, Gerhardt CA, Lehmann V. Romantic relationships and physical intimacy among survivors of childhood cancer. *J Adolesc Young Adult Oncol.* 2020;9:359–66.
- Ussher JM, Perz J, Gilbert E. Changes to sexual well-being and intimacy after breast cancer. *Cancer Nurs.* 2012;35:456–65.
- Schantz LB. Sexuality in men after prostate cancer surgery: a qualitative interview study. *Scand J Caring Sci.* 2017;31:120–7.
- Frederick NN, Recklitis CJ, Blackmon JE, Bober S. Sexual dysfunction in young adult survivors of childhood cancer. *Pediatr Blood Cancer.* 2016;63:1622–8.
- Ussher JM, Perz J, Gilbert E. Women's sexuality after cancer: a qualitative analysis of sexual changes and renegotiation. *Women Therapy Routledge.* 2014;37:205–21.

30. Juraskova I, Butow P, Robertson R, Sharpe L, McLeod C, Hacker N. Post-treatment sexual adjustment following cervical and endometrial cancer: a qualitative insight. *Psychooncology*. 2003;12:267–79.
31. Holmberg SK, Scott LL, Alexy W, Fife BL. Relationship issues of women with breast cancer. *Cancer Nurs*. 2001;24:53–60.
32. Butler L, Banfield V, Sveinson T, Allen K. Conceptualizing sexual health in cancer care. *Western J Nurs Res*. Sage Publications, Inc.; 1998;683–4.
33. Tat S, Doan T, Yoo GJ, Levine EG. Qualitative exploration of sexual health among diverse breast cancer survivors. *J Canc Educ*. 2018;33:477–84.
34. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. *Med J Aust*. 2007;186:224–7.
35. Burns M, Costello J, Ryan-Woolley B, Davidson S. Assessing the impact of late treatment effects in cervical cancer: an exploratory study of women's sexuality. *Eur J Cancer Care*. 2007;16:364–72.
36. Diana P, Esposito S. LGBTQ+ youth health: an unmet need in pediatrics. *Children (Basel)*. 2022;9:1027.
37. Keegan THM, Lichtensztajn DY, Kato I, Kent EE, Wu X-C, West MM, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *J Cancer Surviv*. 2012;6:239–50.
38. Shetty G, Sanchez JA, Lancaster JM, Wilson LE, Quinn GP, Schabath MB. Oncology healthcare providers' knowledge, attitudes, and practice behaviors regarding LGBT health. *Patient Educ Couns*. 2016;99:1676–84.
39. Annon JS. The PLISSIT model: A proposed conceptual scheme for the behavioral treatment of sexual problems. *J Sex Edu Ther*. Taylor & Francis; 1976;2:1–15.

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