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## LGBTQI Sexual Well-Being and Embodiment After Cancer: A Mixed-Methods Study

Amanda Denes<sup>a</sup>, Jane M. Ussher<sup>b</sup>, Rosalie Power<sup>b</sup>, Janette Perz<sup>b</sup>, Samantha Ryan<sup>b</sup>, Alexandra J. Hawkey<sup>a</sup>, Gary W. Dowsett<sup>c</sup>, and Chloe Parton<sup>d</sup>

<sup>a</sup>Department of Communication, University of Connecticut; <sup>b</sup>Translational Health Research Institute, Western Sydney University; <sup>c</sup>Australian Research Centre in Sex, Health and Society, La Trobe University; <sup>d</sup>School of Health, Te Herenga Waka – Victoria University of Wellington

### ABSTRACT

This study examined lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) cancer patients' sexual well-being post-cancer, and the associations between sexual well-being and social support, physical concerns, distress, quality of life (QOL), and coping. We used a mixed-methods approach, including 430 surveys and 103 interviews, representing a range of tumor types, sexual and gender identities, age groups, and intersex status. The findings indicated that LGBTQI people with cancer experience declines in sexual well-being following cancer, which are associated with reduced QOL, greater physical concerns, and lower social support. The perceived helpfulness of coping mechanisms was associated with greater sexual well-being across genders, with cisgender men reporting the sharpest declines in sexual well-being and highest use of coping mechanisms. Across all groups, searching for information online was the most frequently used coping mechanism, with support groups and counseling the most under-utilized. Qualitative findings facilitated interpretation of these results, providing examples of ways in which cancer impacted sexual well-being and how physical changes influence sexual embodiment or desire to engage in sex. Concerns about reduced sexual desire and activity, associated with changes to breasts, vulva, vagina, penis, erectile dysfunction, incontinence, scarring, and stoma, reflect previous findings in the non-LGBTQI cancer population. Unique to this population are the impact of physical changes on LGBTQI embodiment, including disruption to sexual and gender identities, and feelings of disconnection from queer communities. Addressing LGBTQI sexual well-being within oncology healthcare is a matter of sexual and reproductive justice, for a population whose needs are often overlooked within cancer care.



### Introduction


A cancer diagnosis and its subsequent treatment can have a profound impact on individuals' sexual well-being (Mercadante et al., 2010; Perz et al., 2014). This can include reducing patients' physical ability to engage in sexual acts, and changes to one's body image, emotions, and relationship roles (Barros et al., 2023; Gilbert et al., 2013; Olesen et al., 2023). These effects are cited as some of the most poignant and negative long-term outcomes of cancer treatment. Indeed, 57–78% of patients and their partners have reported that cancer negatively impacted their sexual well-being and relationships (Hawkins et al., 2009; Reese et al., 2010; Seguin et al., 2020). Cancer-related sexual concerns and changes have been associated with distress, more severe disease-related symptoms, and lower quality of life (QOL) for cancer patients, in both reproductive and non-reproductive cancers (Levin et al., 2010; Reese et al., 2010; Seguin et al., 2020; Ussher et al., 2012). As such, scholars have called for research aimed at understanding the impact of cancer on sexual well-being and how sexuality concerns can be better integrated into cancer care (Beck et al., 2009; Sadosky et al., 2010; Schubach et al., 2023; Ussher et al., 2020). As previous research on sexual well-being and cancer has focused largely on heterosexual cisgender people, there have also been calls to understand

and address the experiences of lesbian, gay, bisexual, transgender, queer, and/or intersex (LGBTQI) people with cancer (Lisy et al., 2020; Rodrigues et al., 2023; Rosser et al., 2016), which was the aim of the present study.

### *The Sexual Well-Being of LGBTQI People with Cancer*

LGBTQI people with cancer face distinct challenges that are currently under-explored (Cathcart-Rake, 2018; Pratt-Chapman et al., 2021; Quinn et al., 2015), leading researchers to identify this population as a group at “greater risk of inferior psychosocial outcomes following a cancer diagnosis compared with their heterosexual cisgender counterparts” (Lisy et al., 2018, p. 1480). A growing body of research on LGBTQI people's experiences navigating cancer suggests that sexual changes associated with cancer may take a greater toll on some LGBTQI patients, with much of the literature focused on older adult cisgender gay and bisexual men (GBM) with prostate cancer and lesbian and bisexual women with breast cancer. For example, research on prostate cancer indicated that GBM were more bothered by the sexual changes that accompanied cancer than heterosexual men (Ussher et al., 2016; Wassersug et al., 2013). Sexual changes and poorer

**CONTACT** Jane M. Ussher  [j.ussher@westernsydney.edu.au](mailto:j.ussher@westernsydney.edu.au)  Translational Health Research Institute, Western Sydney University, Locked Bag 1797, Penrith, NSW 2752, Australia

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sexual outcomes threatened their gay male identity, made them feel that they were not part of the LGBTQI community (Ussher et al., 2017; Wassersug et al., 2013), and negatively impacted their QOL. Conversely, there is evidence that lesbians with breast cancer reported fewer concerns about sexual issues and perceived less disruption to their sex lives than their heterosexual counterparts (Arena et al., 2007), which may be due to their greater acceptance of bodily changes (Fobair et al., 2001) and broader repertoire of sexual activities, other than penetrative sex.

For some trans<sup>1</sup> people, cancer can disrupt the gender affirmation process by bringing attention to body parts that are discordant with their gender identity, or through embodied change following cancer treatment, creating or increasing gender dysphoria (Brown & McElroy, 2018; Taylor & Bryson, 2016), which may impact sexual well-being. However, trans people also identify unique benefits of cancer treatment in affirming their identities (e.g., removing body parts incongruent with their gender identity), even in the face of stressors related to navigating the medical landscape as trans persons (Alpert et al., 2021; Ussher, Power, et al., 2023). There is no research that has examined the post-cancer sexual well-being of people with an intersex variation. Given the unique and varied experiences of cancer patients within the LGBTQI community, research is needed to address cancer-related sexual changes among a broader and more diverse sample of LGBTQI people navigating various forms of cancer, across gender, sexuality, and age groups (Lisy et al., 2020).

Understanding sexual well-being for LGBTQI people with cancer requires an examination of the psychosocial milieu in which such changes are managed. Among people with both reproductive and non-reproductive cancers in the general cancer population, lower QOL and greater depression have been associated with poorer sexual functioning (Frankland et al., 2020; Perz et al., 2014; Seguin et al., 2020). Patients have also reported both psychosocial (e.g., stress, fear, low self-esteem, lack of confidence) and physical (e.g., genital pain, sexual dysfunction, body and appearance changes) factors as impacting sexual frequency and sexual well-being after cancer (Gilbert et al., 2011; Ussher et al., 2015). Social and relational support is a known correlate of sexual health (Del Mar Sánchez-Fuentes et al., 2016) and sexual well-being (Collaço et al., 2018; Gorman et al., 2020). For example, for female breast cancer patients, greater social support from family and friends was associated with fewer sexual adjustment problems since becoming ill (Kim & Jang, 2020). Additionally, support in discussing sexuality and maintaining a positive image of oneself has been identified as an important aspect of cancer care (Canzona et al., 2019; Liberacka-Dwojak & Izdebski, 2021; Rasmusson & Thome, 2008). Social support can also help mitigate the impact of discrimination on negative health outcomes for LGBTQI people (Kamen & Darbes, 2018; Meyer, 2003) and LGBTQI cancer patients (Power et al., 2022). Taken together, this is convincing evidence that social support, physical concerns, and

psychosocial factors impact sexual well-being for people with and without cancer, but more research is needed to address how such factors contribute to the sexual well-being of LGBTQI people with cancer.

Sexual well-being may also be associated with the ability to cope with sexual changes that accompany cancer. Minority stress theory explains that LGBTQI people experience health disparities due to increased social stressors arising from stigmatization, with coping being an important factor mitigating the effect of stress on health outcomes (Meyer, 2003). Enacting various coping mechanisms, such as engaging in therapy, or interventions aimed at improving sexual communication and emotional support, can garner positive effects for patients and their partners. The flexible model of coping with sexual dysfunction in chronic illness (Barsky et al., 2006) further posits that broadening one's definition of sexual activity or sexual function and its role in a person's self-concept can benefit psychosocial outcomes, such as relationship and sexual satisfaction. Flexibility and renegotiation may be both encouraged and manifested through various coping behaviors, such as talking with healthcare professionals, participating in support groups or counseling, redefining sex, embracing other forms of intimacy, and changing sexual practices, including using sexual aids, medications, and medical devices (Liberacka-Dwojak & Izdebski, 2021; Schubach et al., 2023; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013).

In one study, GBM were more likely than heterosexual men to have tried sexual or medical aids and to have sought information on coping with the effects of cancer on their sexuality through support groups, counseling, and the Internet (Ussher et al., 2019). Additionally, research exploring lesbian and bisexual women's experiences suggested "strengths in sexual minority women's coping" compared with heterosexual women, such as greater emotional expression and less hopelessness, avoidance, and denial (Boehmer et al., 2012, pp. 147–148). Lesbians with breast cancer have also reported receiving more support from romantic partners than their heterosexual counterparts (Arena et al., 2007; Fobair et al., 2001), which may have impacted how they coped with sexual changes related to cancer. However, coping efforts may be influenced by the systemic invisibility of LGBTQI people in mainstream cancer information resources (Ussher, Ryan, et al., 2023), absence of LGBTQI inclusive support groups, and perceptions of discrimination in healthcare (Kokay et al., 2023; Squires et al., 2022; Ussher, Power et al., 2022).

Taken together, these studies point to further research being needed to examine the impact of cancer and cancer treatment on LGBTQI people's sexual well-being, as well as the coping mechanisms employed by LGBTQI people to manage cancer-related sexual changes, across diverse sexualities and genders, including a range of cancer types and age groups. As a consequence, the present study was guided by the following aims:

Aim 1: To determine if sexual well-being changes from pre- to post-cancer for LGBTQI people with cancer and whether gender impacts sexual well-being.

Aim 2: To identify psychosocial factors and physical concerns associated with sexual well-being and whether such associations vary by gender.

<sup>1</sup>We use the term "trans" as an umbrella that refers to individuals who identify as transgender, gender diverse, or non-binary, as recommended by community partners and stakeholders on this project.

Aim 3: To identify coping mechanisms employed by LGBTQI people with cancer in managing sexual changes and determine whether coping is associated with sexual well-being or impacted by gender.

## Method

### Study Design

This mixed-methods study was part of a larger program of research – the *Out with Cancer Study* – examining LGBTQI experiences of cancer and cancer care from the perspectives of LGBTQI people with cancer, carers, and healthcare professionals (Power et al., 2022; Ussher, Allison, et al., 2022, 2023; Ussher, Perz, et al., 2022; Ussher, Power, et al., 2022, 2023; Ussher, Ryan, et al., 2023). This paper presents data from an online survey and semi-structured interviews related to LGBTQI cancer patients' sexual well-being. The project was underpinned by an integrated knowledge translation (iKT) framework (Graham et al., 2006), with a 46-member stakeholder advisory group actively involved in co-design and co-production throughout all stages of the project. The group comprised LGBTQI cancer survivors and carers, cancer healthcare professionals, and representatives from LGBTQI health and cancer support organizations. Ethics approval for this study was granted by Western Sydney University University's Human Research Ethics Committee (ref. no. H12664). Secondary approval was obtained from ACON, formally Aids Council of NSW, an LGBTQI community health and advocacy organization that collaborated as a partner in this study (ref. no. 2019/09). All methods were carried out in accordance with relevant guidelines and regulations outlined in the Declaration of Helsinki. All participants provided written consent.

### Participants and Recruitment

Participants were eligible for this study if they: (a) had been diagnosed with cancer or had undergone a medical intervention related to cancer risk; (b) identified as LGBTQI; and (c) were at least 15 years old. The study was advertised through cancer and LGBTQI community organizations, including the study partner organizations, cancer research databases (Register 4, ANZUP), cancer support groups, at in-person LGBTQI events, and via social media (Facebook, Twitter, Instagram). Snowball sampling was also used, asking participants to share the survey link with eligible contacts. The study was open internationally, although recruitment focused on Australia and other English-speaking countries such as the USA, UK, New Zealand, and Canada. Data were collected between September 2019 and September 2021.

### Quantitative Measures

The survey was administered online, facilitating anonymity, and included a combination of validated and unvalidated measures, described in detail elsewhere (Ussher, Allison, et al., 2022). In addition to demographic information, the

measures used in the current study are described in the following sections.

*Sexual well-being* was assessed using eleven items from the EORTC Sexual Health Questionnaire (EORTC SHQ-C22 (Greimel et al., 2021; Oberguggenberger et al., 2018); Participants rated the extent to which they experienced sexual satisfaction and concerns before and after cancer, using a four-point Likert-type scale (1 = *not at all* to 4 = *very much*; individuals who answered "N/A" were excluded). Before cancer ratings were retrospective. A principal components analysis indicated that six of the eleven items loaded onto a factor indicative of sexual satisfaction (e.g., "Has sexual activity been enjoyable for you?"), with loadings of .70 or higher. The six items were retained as a measure of sexual well-being (pre-cancer  $\alpha = .86$ ; post-cancer  $\alpha = .89$ ).

Ten items from the Kessler Psychological Distress Scale (K10 (Kessler et al., 2002); assessed *distress*. Participants rated how frequently they had experienced various distressing feelings over the past 30 days (e.g., "that everything was effort"), on a five-point Likert scale ranging from 1 = *none of the time* to 5 = *all of the time* ( $\alpha = .93$ ). *Quality of life* (QOL) was assessed using a single item (i.e., "How would you rate your overall quality of life during the past week?") from the EORTC-QLQ-C30 (Aaronson et al., 1993) on a scale ranging from 1 = *very poor* to 7 = *excellent*.

*Social support* was assessed with the five-item social support subscale of the Health Literacy Questionnaire (Osborne et al., 2013). Participants indicated the extent to which they agreed or disagreed with statements regarding support from their network (e.g., "When I feel ill, the people around me really understand what I am going through"). Items were assessed on a Likert scale ranging from 1 = *strongly agree* to 5 = *strongly disagree*, with higher scores indicating stronger support ( $\alpha = .84$ ).

The remaining items used in this analysis were derived from existing LGBTQI surveys (Ussher et al., 2016). *Physical concerns* were assessed with 14 items that asked participants, "Since your cancer/cancer risk intervention, have you had concerns about changes to your body relating ... " followed by specific physical concerns such as muscle loss/wastage, hair loss, weight gain, and incontinence (1 = *not at all*, 4 = *very much*). *Coping with cancer-related changes* to sexual well-being was assessed with seven items that asked participants, "Have you tried anything to manage changes to your sexual well-being after your cancer/cancer risk intervention, and how helpful was this?" followed by coping mechanisms such as talking to a healthcare professional, changing sexual practices, and looking up information on the internet (Gilbert et al., 2016; Ussher et al., 2016).

### Qualitative Measures

The online survey included open-ended questions at the end of each measure asking, "Is there anything you would like to tell us about this?" Survey participants were invited to take part in an interview for the purpose of understanding their experiences in greater depth. One-hour, semi-structured interviews,



conducted via phone or videoconferencing software, were tailored to participants' experiences based on their survey responses. The interviews were conducted by LGBTQ members of the research team trained in semi-structured interviewing, supervised by the lead investigator (JU). The interview schedule asked about participants' experiences of cancer and cancer care, including their interactions with healthcare professionals, their support networks, and how cancer had impacted their lives, including sexual well-being (see Supplementary Table S1). Participants were paid 30 AUD for taking part in the interview.

## Analysis

### Quantitative Analysis

All statistical analyses were conducted using SPSS version 29. Initial data inspection indicated that the study's primary variables were within the acceptable ranges (skewness <3, kurtosis <10 (Kline, 2020); Aim 1 was addressed with a paired samples *t*-test to examine potential differences between pre- and post-cancer sexual well-being for the sample. A repeated measures analysis of variance (ANOVA) was employed to compare differences in sexual well-being from pre- to post-cancer by gender. Aim 2 was assessed with multiple regression to determine whether social support, physical concerns, distress, and QOL were associated with sexual well-being post-cancer. To address Aim 3, bivariate correlations were used to examine whether specific physical concerns were associated with sexual well-being post-cancer, and ANOVA was used to assess differences in physical concerns by gender. To examine whether the association between physical concerns and sexual well-being post-cancer varied by gender, a series of moderation models were tested using Hayes (2013) PROCESS Macro. Descriptive statistics and frequencies were examined to address the prevalence of coping mechanisms used to manage cancer-related sexual concerns. Independent samples *t*-tests were used to determine whether the use of specific coping mechanisms was associated with sexual well-being post-cancer, and a two-way ANOVA was used to determine if this association varied by gender. Lastly, bivariate correlations were used to assess the relationship between the perceived helpfulness of a coping mechanism and sexual well-being.

### Qualitative Analysis

All interviews were audio-recorded, transcribed, and checked for accuracy. During this process, identifying information was removed from the transcripts and participants' names were replaced with pseudonyms. Open-ended survey and interview data were organized in the software NVivo and analyzed using reflexive thematic analysis (Braun & Clarke, 2019). Within this framework, themes are not "discovered" in the data, but are the result of prolonged data immersion, consideration, and reflection – an active and generative process (Braun & Clarke, 2019, p. 594). Throughout our analysis, we engaged in a process of reflexivity. This involved being aware of the interactions between the researchers and participants and critically reflecting on how our own backgrounds, experiences, and assumptions influenced the research process (Finlay & Gough, 2003). The research team and advisory group included individuals of

diverse gender and sexual identities, cultural backgrounds, and age groups, including those who had experienced cancer and those who had not, representing a range of professional, academic, community, and consumer expertise.

Through a collaborative process with a number of members of the stakeholder advisory group and research team, a subset of interviews and open-ended survey data were read through line by line and notes made to identify first-order codes. The coders volunteered to undertake the process and represented expertise in LGBTQI health, cancer, and sexual health. Through iterative discussion, codes with commonalities were organized into higher-order codes and a comprehensive coding framework was developed and applied to all data. Data under each code were then summarized to facilitate the identification and development of themes, with the stakeholder advisory group again actively involved in the interpretation of data. The themes were further refined, including incorporating feedback from the stakeholder advisory group on language and interpretation. Throughout this process, the authors of this paper reflected upon how our identities as White, middle class, Western, queer and non-queer, cis-gendered researchers shape the lens with which we bring to the analysis. In this paper, thematic qualitative data are integrated within each section of the quantitative findings, to provide insight into subjective experiences. Brief demographic descriptors are presented in the text for longer quotes, and the full quote for shorter extracts is presented in supplementary tables, referenced by a superscript letter.

## Results

### Participants

A sample of 430 LGBTQI people who currently or had previously had cancer with a range of tumor types completed the survey. One hundred and seventy-nine people volunteered to be interviewed, and 104 participants were invited to interview, representing a diversity across gender (cisgender, trans, and non-binary), sexuality (gay, lesbian, bisexual, queer, pansexual), age, and tumor type. Initial inspection of the data indicated that some participants may have confused a response of "not at all" with "not applicable" in response to two questions regarding physical changes. As such, we removed responses (for specific items) for individuals who indicated the following: (1) individuals who identified as cisgender women with no intersex variation were removed if they indicated a response other than "not applicable" to the question about changes related to penis length ( $n = 6$ ); (2) individuals who identified as cisgender men with no intersex variation were removed if they indicated a response other than "not applicable" to the question about changes related to early menopause ( $n = 19$ ). Attention checks confirmed that other survey items for these participants were appropriate. Combined with participants who opted not to respond to questions, there was some missing data for each of the study variables. SPSS excludes cases with a missing value for any of the variables used in each analysis. As such, for each analysis, only participants with no missing data for the variables for that given analysis were included.

Tables 1 and 2 present the demographic and cancer characteristics of survey respondents, respectively. Most participants were cisgender (83.9%; 50.2% cisgender women, 33.7% cisgender men), White (85.2%), older adults (77.9%), living in Australia (72.3%), and identified as lesbian, gay, or homosexual (73.7%). Greater diversity was evident in participants' geographical location (54.4% urban; 33.8% regional; 11.7% rural or remote), and cancer types (see Table 2). A minority of participants identified as trans or non-binary (14.7%), bisexual (9.5%), or queer (10.7%); 7.2% reported an intersex variation. A minority identified as Australian Aboriginal, Torres Strait Islander, or Māori (indigenous person of Aotearoa/New Zealand; 2.1%), Asian (2.6%), or from a mixed ethnic background (4.5%).

Means, standard deviations, and correlations for the primary study variables are presented in Table 3. Preliminary analyses revealed few significant differences between subgroups within the group broadly defined as trans and non-

binary. A notable exception was that QOL varied between subgroups, such that nonbinary or genderfluid participants reported lower QOL than transgender women. However, given the generally non-significant differences in the key study outcomes between the subgroups and the small number of individuals within some subgroups (e.g., transgender women  $n = 9$ , transgender men  $n = 3$ ), these subgroups were combined as trans for the primary analyses.

### Changes in the Sexual Well-Being of LGBTQI People with Cancer

The first aim of the study was to determine if sexual well-being changes from pre- to post-cancer for LGBTQI people with cancer. As indicated in Table 4, ratings of overall sexual well-being significantly decreased from pre- ( $M = 3.02$ ,  $SD = .78$ ) to post-cancer ( $M = 2.34$ ,  $SD = .87$ ). Additionally, examination of each of the six facets of sexual well-being that emerged from the principal

**Table 1.** Demographic characteristics of survey participants.

Demographic Characteristic	<i>N</i>	<i>M (SD), range</i>
Age at time of study (years)	429	52.5 (15.7), 16–92
	<i>N</i>	<i>n (%)</i>
Country	430	
Australia		311 (72.3%)
United States of America		62 (14.4%)
United Kingdom		29 (6.7%)
New Zealand		8 (1.9%)
Canada		7 (1.6%)
Other		13 (3.0%)
Location	429	
Urban		234 (54.5%)
Regional		145 (33.8%)
Rural or remote		50 (11.7%)
Race/ethnicity	425	
White		362 (85.2%)
Asian		11 (2.6%)
Australian Aboriginal, Torres Strait Islander or Maori		9 (2.1%)
Mixed background		19 (4.5%)
Other/unclear background		24 (5.6%)
Gender	430	
Cisgender women		216 (50.2%)
Cisgender men		145 (33.7%)
Trans and non-binary <sup>a</sup>		63 (14.7%)
Different identity		6 (1.4%)
Sexuality	430	
Lesbian, gay, or homosexual		317 (73.7%)
Bisexual		41 (9.5%)
Queer		46 (10.7%)
Straight or heterosexual		10 (2.3%)
Different or multiple identities		16 (3.7%)
Intersex variation	430	
Yes		31 (7.2%)
No		388 (90.2%)
Prefer not to answer		11 (2.6%)
Relationship status <sup>b</sup>	368	
Not in a relationship		126 (34.2%)
Casually dating		16 (4.3%)
Relationship with one other person		216 (58.7%)
Multiple relationships		16 (4.3%)
Education	422	
Less than secondary		10 (2.3%)
Secondary		45 (10.5%)
Some post-secondary		58 (13.5%)
Post-secondary		317 (73.7%)

<sup>a</sup>37 (8.6%) non-binary or genderfluid, 13 (3.0%) trans women, 8 (1.9%) trans men; <sup>b</sup>Participants could indicate multiple options if applicable.

**Table 2.** Cancer characteristics of survey participants.

Demographic/Cancer Characteristic	<i>N</i>	<i>M (SD), range</i>
Age at diagnosis (years)	363	46.3 (15.3), 1–79
	<i>N</i>	<i>n (%)</i>
Medical intervention for cancer risk	430	74 (17.2%)
Cancer diagnosis (first)	370	
Brain		11 (3.0%)
Breast		90 (24.3%)
Cervical		11 (3.0%)
Colorectal		17 (4.6%)
Head/neck		14 (3.8%)
Leukaemia		17 (4.6%)
Lymphoma		24 (6.5%)
Ovarian		17 (4.6%)
Prostate		59 (15.9%)
Skin		25 (6.8%)
Uterine		23 (6.2%)
Other		58 (15.7%)
Not sure or unknown		4 (1.1%)
Cancer stage	369	
Localised		228 (61.8%)
Regional		88 (23.8%)
Distant/metastatic		32 (8.7%)
N/A (e.g. blood cancer)		5 (1.4%)
Not sure or unclear		16 (4.3%)
Treatment status	370	
No treatment yet		37 (10.0%)
On active curative treatment		37 (10.0%)
On maintenance treatment		60 (16.2%)
In remission		217 (58.6%)
Receiving palliative care (no further active treatment)		4 (1.1%)
Not sure		8 (2.2%)
Subsequent cancers <sup>a</sup>	370	
Recurrence		57 (15.4%)
New primary cancer		40 (10.8%)
Other health condition, disability or impairment	338	135 (39.9%)

<sup>a</sup>Participants could indicate multiple options if applicable.

**Table 3.** Means, standard deviations, and correlations for continuous study variables.

	<i>M</i>	<i>SD</i>	1	2	3	4	5
1. Sexual Well-Being Pre-Cancer	2.99	.77	–				
2. Sexual Well-Being Post-Cancer	2.35	.88	.30***	–			
3. Social Support	3.88	.92	.27***	.34***	–		
4. Number of Physical Concerns	5.31	2.91	–.02	–.28***	–.18**	–	
5. Distress	1.23	1.12	–.14*	–.31***	–.47***	.37***	–
6. QoL	4.70	1.57	.20***	.33***	.42***	–.30***	–.60***

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ .

**Table 4.** Rating of sexual well-being from pre- to post-cancer.

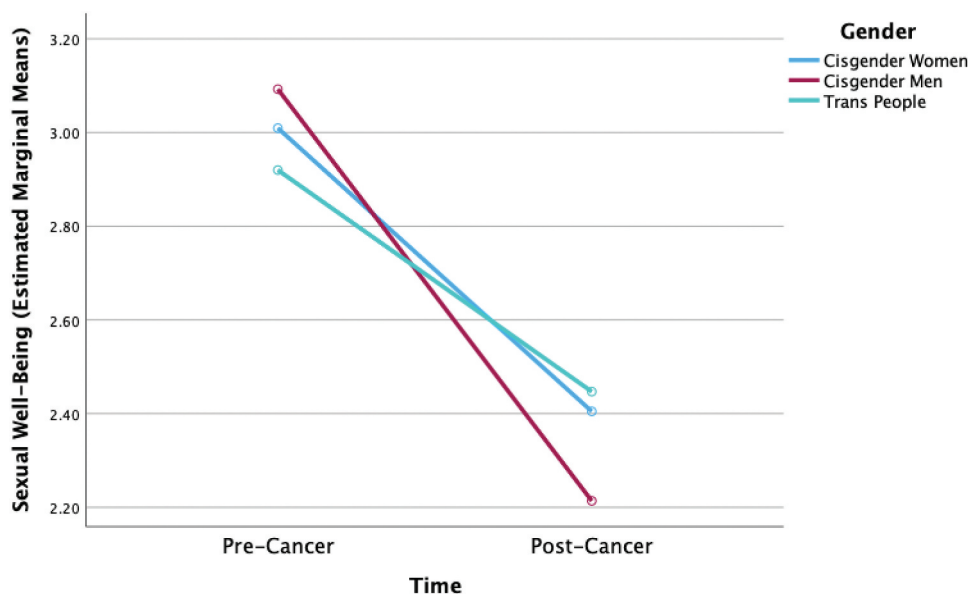
	<i>t(df)</i>	<i>p</i>	<i>M (SD)</i>	
			Pre-Cancer*	Post-Cancer
Overall Sexual Well-Being	11.51(278)	<.001	3.02 (.78)	2.34 (.87)
Physical Intimacy	8.65(260)	<.001	3.12 (.95)	2.51 (1.13)
Sexual Desire	12.47(262)	<.001	3.09 (.94)	2.15 (1.05)
Enjoy Sexual Activity	10.04(235)	<.001	3.30 (.85)	2.52 (1.07)
Ability to Reach Orgasm	9.715(246)	<.001	3.16 (.92)	2.42 (1.05)
Communication about Sexual Issues	3.70(218)	<.001	2.83 (1.03)	2.56 (1.09)
Sex Life	11.51(278)	<.001	2.88 (1.00)	2.05 (.78)

\*Pre-cancer scores were retrospective.

components analysis indicated a significant decrease from pre- to post-cancer (see Table 4).

We also examined whether changes in sexual well-being pre- to post-cancer varied by gender. A repeated measures

ANOVA revealed that the interaction between gender and time was significant,  $F(2, 272) = 3.25$ ,  $p = .04$ ; Box's  $M = 5.65$ ,  $p = .47$ . Post hoc paired-samples  $t$ -tests indicated significant declines for each group: cisgender men ( $p < .001$ ;  $M_1 = 3.09$ ,



**Figure 1.** Interaction of time and gender on post-cancer sexual well-being.

$M_2 = 2.21$ ); cisgender women ( $p < .001$ ;  $M_1 = 3.01$ ,  $M_2 = 2.41$ ); and trans people ( $p = .01$ ;  $M_1 = 2.92$ ,  $M_2 = 2.45$ ). The majority of participants with an intersex variation identified with one of these gender groupings and were not analyzed separately due to the small subsample size. Of 31 intersex participants, 6 identified as cisgender women, 6 as cisgender men, 14 as trans, and 5 did not respond. As depicted in Figure 1, cisgender men experienced the steepest decline in sexual well-being from pre- to post-cancer, followed by cisgender women, then trans people. However, an ANOVA indicated that sexual well-being post-cancer (both the overall mean and individual items) did not significantly vary by gender (see Table 5).

Given the potential impact of age, relationship status, and cancer type (i.e., reproductive vs. non-reproductive) on sexual well-being, several post hoc analyses were conducted to determine whether the interaction of gender and time with age, relationship status, or cancer type (in separate models) impacted sexual well-being. A repeated measures analysis of covariance (ANCOVA) revealed that the three-way interaction between gender, age, and time was not significant ( $p = .09$ ). A closer examination of the simple slopes indicated that the interaction of time and age was not significant for cisgender women ( $p = .87$ ) or cisgender men ( $p = .36$ ), but it was significant for trans people ( $p = .02$ ).

Additional analyses indicated that age was positively correlated with decreases in sexual well-being from pre- to post-cancer for trans people (i.e., the older an individual, the more they experienced declines in sexual well-being;  $r = .40$ ,  $p = .02$ ).

A second repeated measures ANCOVA revealed that neither the three-way interaction between gender, relationship status (in a relationship vs. not in a relationship), and time ( $p = .66$ ), nor the two-way interaction between relationship status and time ( $p = .06$ ), was significant. A final repeated measures ANCOVA revealed that the three-way interaction between gender, cancer type (reproductive vs. non-reproductive), and time was not significant ( $p = .62$ ), nor was the two-way interaction between cancer type and time significant ( $p = .38$ ).

#### **“Death of Desire:” Low Libido and Reduced Desire for Sex**

The qualitative analyses provided insight into the subjective experience of these sexual changes (see Supplementary Table S2). Reduction or complete cessation of sexual activity post cancer was commonly reported across participant groups, described as a “loss of desire and libido”<sup>a</sup>, attributed to “chemo and radiation,” which means “you don’t feel sexy

**Table 5.** Sexual well-being post-cancer by gender.

Sexual Well-Being	F	p	M (SD)		
			Cisgender Women	Cisgender Men	Trans People
Overall Sexual Well-Being	1.76	.17	2.42 (.84) <sup>†</sup>	2.21 (.88) <sup>†</sup>	2.44 (1.01)
Physical Intimacy	2.12	.12	2.66 (1.09) <sup>†</sup>	2.39 (1.18) <sup>†</sup>	2.31 (1.12)
Sexual Desire	1.82	.16	2.09 (1.01) <sup>†</sup>	2.15 (1.05)	2.47 (1.24) <sup>†</sup>
Enjoy Sexual Activity	1.00	.37	2.63 (1.03)	2.42 (1.14)	2.48 (1.09)
Ability to Reach Orgasm	1.47	.23	2.53 (1.03) <sup>†</sup>	2.28 (1.05) <sup>†</sup>	2.41 (1.13)
Communication about Sexual Issues	1.93	.15	2.65 (1.09) <sup>†</sup>	2.36 (1.09) <sup>†</sup>	2.73 (1.14)
Sex Life	1.54	.22	2.14 (1.04)	1.91 (1.05)	2.17 (1.10)

Across rows, <sup>†</sup> = categories different at  $p < .10$ .



when you think that's happening in your body."<sup>a</sup> (Survey, 38, cisgender man, gay, colorectal). Another participant noted:

I have more difficulty being aroused. All the chemo destroyed a lot of interest as well. And then definitely the hormone treatment just suppresses your estrogen being taken up by your body, so it impacts everything. (Mary, age 54, cisgender, lesbian, breast)

"Lack of attraction or motivation"<sup>b</sup> (Brianna, 26, cisgender woman, queer, lymphoma) or "absolutely no sexual interest at all"<sup>c</sup> (Troy, 71, cisgender man, gay, prostate) were also associated with exhaustion<sup>a</sup> and the "psychological weight" of cancer and cancer treatment. For example, Dylan (age 32, non-binary, gay, leukemia) told us:

For sex itself, fine. I think it's reduced my interest in it. Because . . . I'm just . . . tired all the time, concerned about my health, all that kind of stuff. You know, the psychological weight of it has kind of decreased my libido.

These "changes in sex drive and performance"<sup>d</sup> (Survey, 72, cisgender man, gay, prostate) meant that even when patients were given permission to engage in post-treatment sexual activity by their physicians, some reported, "I don't like to. I don't want to, so I don't"<sup>e</sup> (Anita, 34, cisgender woman, lesbian, uterine). These sexual changes were not welcomed by participants, who described them as "frustrating"<sup>b</sup>, "quite a shock"<sup>c</sup>, and "impacting on my previous casual sex life"<sup>d</sup>, leading some to experience a sense of mourning:

We don't have the same level of sexual intimacy that we used to have and that, psychologically for me, that's hard to deal with. There's a lot of psychological mourning that takes place, sort of mourning the loss of this thing that I had for all my life and that that's no longer there. And I think it makes my husband feel sad, too. (Fredrick, 57, cisgender man, gay, prostate)

Others accepted sexual changes, saying that they could "cope with that"<sup>f</sup> if it meant that they could "live another 10 or 15 years longer"<sup>f</sup> following surgery (Neal, 68, cisgender man, gay, prostate), or because "there's nothing you can do about that, and that sucks, but it is what it is"<sup>g</sup> (Alicia, 65, cisgender woman, lesbian, breast).

### Post-Cancer Embodiment and Social Support: Factors Associated with Sexual Well-Being

The second aim of the study was to identify psychosocial factors and physical concerns associated with sexual well-being and whether such associations varied by gender. As indicated in Table 6, greater social support ( $\beta = .24, p = .001$ ), fewer physical concerns ( $\beta = -.15, p = .02$ ), and greater QOL ( $\beta = .21, p = .01$ ) were significantly associated with greater sexual well-being post-cancer.

Bivariate correlational analysis examined whether specific physical concerns were associated with sexual well-being (Table 7). For most of the 14 physical changes (except weight loss, hair loss, and stoma), post-cancer sexual well-being was negatively associated with the extent to which a person reported the physical concern. An ANOVA revealed that the number of reported physical concerns (out of 14) did not significantly vary by gender,  $F(2, 296) = 2.65, p = .07$ . Univariate tests indicated that cisgender women ( $M = 5.56,$

**Table 6.** Social support, physical concerns, distress, and QoL predicting sexual well-being post-cancer.

	Sexual Well-Being		
	$\beta$	$t$	$p$
Social Support	.24	3.46	.001
Physical Concerns	-.15	-2.39	.02
Distress	-.002	-.03	.98
QoL	.21	2.62	.01
	$R^2$	$F$	$p$
Overall Model Statistics	.21	15.19	<.001

$SD = 2.99$ ) reported significantly more physical concerns than cisgender men ( $M = 4.76, SD = 2.74; p = .03$ ). However, the number of physical concerns reported by trans people ( $M = 5.60, SD = 2.81$ ) was not significantly different from cisgender women ( $p = .94$ ) or cisgender men ( $p = .13$ ). Examining each domain of physical concerns, significant differences emerged between cisgender women and cisgender men (see Table 7). Not surprisingly, cisgender women reported significantly more scarring, early menopause, change in breast sensitivity, and loss of one or both breasts compared with cisgender men. Similarly, cisgender men reported significantly more incontinence and stoma than cisgender women. Cisgender men reported marginally less breast sensitivity and more shortened penis than trans people.

A series of moderation models were tested to determine whether the association between post-cancer physical concerns and sexual well-being varied by gender. One model was tested for each of the 14 physical concerns, in which the physical concern was the predictor variable, post-cancer sexual well-being was the dependent variable, and gender was the multi-categorical moderator. Most of the moderation models indicated that gender did not significantly impact the association between physical concerns and sexual well-being ( $ps = .40-.998$ ). However, significant interactions emerged for physical changes involving incontinence ( $R^2$  change = .03,  $F = 2.99[2, 206], p = .05$ ) and stoma ( $R^2$  change = .07,  $F = 3.33[2, 89], p = .04$ ). An examination of the conditional effects indicated that, for cisgender men, the effect of incontinence on sexual well-being was significant ( $b = -.40, SE = .09, p < .001$ ), but the effect was not significant for cisgender women ( $b = -.10, SE = .09, p = .25$ ) or trans people ( $b = -.22, SE = .14, p = .12$ ). Similarly, an examination of the conditional effects of the association between stoma and sexual well-being indicated that the effect was significant for cisgender men ( $b = -.37, SE = .17, p < .001$ ), but the effect was not significant for cisgender women ( $b = .69, SE = .66, p = .30$ ) or trans people ( $b = .43, SE = .32, p = .18$ ).

### "We're in This Together:" Supportive Partners and Communication

The qualitative analyses identified the nature and function of social support in relation to sexual changes after cancer (see Supplementary Table S3). Partner "understanding"<sup>h</sup> and "acceptance"<sup>i</sup> of changed libido or changed sexual functioning were described as key attributes of "supportive"<sup>j</sup> relationships. For example, participants described their partners as: "She's extremely understanding . . . There's no sex . . . but we are very, very affectionate"<sup>h</sup> (Virginia, 48, cisgender woman,

**Table 7.** Associations between physical concerns and Post-Cancer Sexual Well-Being, and differences in physical concerns by gender.

Physical Concern	<i>r</i>	<i>p</i> (correlation)	<i>F</i>	<i>p</i> (ANOVA)	<i>M (SD)</i>		
					Cisgender Women	Cisgender Men	Trans People
Muscle loss/wastage	-.29	<.001	1.34	.26	2.16 (1.00)	2.38 (1.12)	2.16 (1.00)
Reduced body strength	-.24	<.001	.55	.58	2.47 (1.01)	2.35 (1.08)	2.32 (1.03)
Reduced mobility	-.23	<.001	.21	.81	2.04 (.98)	2.06 (1.07)	2.16 (1.01)
Weight loss	-.13	.06	1.07	.35	1.44 (.85)	1.54 (.83)	1.67 (.85)
Weight gain	-.14	.04	1.42	.24	2.44 (1.14)	2.30 (1.20)	2.09 (1.01)
Hair loss	-.01	.88	2.05	.13	1.96 (1.10) <sup>†</sup>	1.67 (1.03) <sup>†</sup>	1.74 (.86)
Scarring	-.16	.01	3.41	.04	2.26 (1.22) <sup>a</sup>	1.87 (1.12) <sup>a</sup>	2.21 (1.14)
Incontinence	-.28	<.001	4.30	.02	1.74 (.92) <sup>a</sup>	2.17 (1.14) <sup>a</sup>	1.91 (1.16)
Stoma	-.12	.26	3.98	.02	1.10 (.45) <sup>a</sup>	1.58 (1.06) <sup>a</sup>	1.32 (.95)
Early menopause	-.28	.001	3.04	.05	2.59 (1.23) <sup>a</sup>	1.56 (.88) <sup>at</sup>	2.38 (1.32) <sup>†</sup>
Change in breast sensitivity	-.26	.001	4.17	.02	2.20 (1.21) <sup>a</sup>	1.50 (.84) <sup>at</sup>	2.13 (1.19) <sup>†</sup>
Loss of one or both breasts	-.22	.03	3.72	.03	2.24 (1.24) <sup>a</sup>	1.40 (1.06) <sup>a</sup>	1.76 (1.14)
Shortened penis	-.33	.003	2.04	.14	1.00 ( <i>n</i> = 1)	2.26 (1.19)	1.72 (1.02)
Change in genital sensitivity	-.40	<.001	2.43	.09	2.11 (1.04) <sup>†+</sup>	2.42 (1.14) <sup>†</sup>	2.54 (1.28) <sup>†</sup>

Correlations (*r*, *p*[correlation]) are between each physical concern and post-cancer sexual well-being. The ANOVA (*F*, *p*[ANOVA]) indicates significant differences when comparing the three groups (i.e., cisgender women, cisgender men, trans people). Across rows, categories with <sup>a</sup> indicate that they are significantly different from one another at *p* < .05 and categories with <sup>†</sup> or <sup>+</sup> are different at *p* < .10.

lesbian, lymphoma) and “He just accepted the fact that maybe I wouldn’t want intimacy as much as we normally did. But he knew it was just part of the process and the disease and the treatment”<sup>ii</sup> (Hector, 86, cisgender man, gay, leukemia). Communication about sex through “having conversations”<sup>ik</sup> was also identified as a central component of relational support. As Barbara (48, cisgender woman, lesbian, endometrial) said, “It is something we’ve had to negotiate and be open with each other about and talking about”<sup>l</sup>. These conversations facilitated other forms of “physical intimacy”<sup>hl</sup> such as “kissing, hugging, holding hands”<sup>h</sup>, or acceptance of the reduction of sexual activity<sup>i</sup>. The consequence was that sexual changes did not threaten relationships, particularly if the preexisting relationship context was “solid.”

I don’t think it impacted negatively on our relationship, because we were just such a solid unit. Sex went out the door because we were incapable of it after a while. It put immense pressure on our relationship, but not to the extent that our relationship was threatened or anything. I guess we were just solid. (Archer, 59, cisgender woman, lesbian, bowel)

In contrast, participants who “didn’t have a supportive partner” reported that physical changes “had a huge impact on my relationship and sex life,” because the partner “wasn’t patient with me and she wasn’t kind about [sexual changes]” (Victor, 47, trans man, straight, ovarian).

### The Broken Body: The Impact of Changes to Sexual Embodiment

The qualitative analyses identified ways in which physical changes resulting from cancer treatment impacted sexual embodiment and subjectivity (see Supplementary Table S4). Breast changes following mastectomy were described as producing “extreme body issues”<sup>mm</sup> due to “scars and only one working breast and nipple”<sup>mm</sup>, “lack of nipples”<sup>nn</sup> and “breast deformation”<sup>oo</sup>. This was reported to have made some participants experience difficulties in “feeling comfortable with my body”<sup>nn</sup> (Survey, 38, non-binary, queer, medical intervention), or feeling “less of a woman”<sup>oo</sup>; “this greatly affected my image as a woman and gave me extreme body issues”<sup>mm</sup>

(Survey, 33, cisgender woman, queer, breast). However, for participants who “never wanted the shape of a female body” mastectomy could be “freeing.”

I never wanted the shape of a female body, especially not breasts. I would hide and flatten my breasts and researched “top surgery” from time to time. Then, I was diagnosed with breast cancer, and it allowed me to state what surgery I would prefer – a bilateral mastectomy. I didn’t want to get cancer. But I’m happier without breasts. It’s freeing. (Christine, 53, cisgender woman, lesbian, breast)

Erectile dysfunction and penis shrinkage<sup>p</sup> combined with absence of ejaculate<sup>p</sup> and persistent urinary incontinence following prostate cancer led to avoidance of sex: “If I stand up during sexual activity I leak [urine] the whole time. These days at the moment [it is] just masturbation” That’s all I can do”<sup>q</sup> (Carl, 63, cisgender man, gay, prostate). Other participants reported feeling “suicidal.”

I thought I would have been okay after the surgery, but I never got an erection, and I didn’t realize the importance of cum during sex. I felt that our relationship had changed from being sexual partners to just being friends. This and the persistent urinary incontinence made me feel suicidal. (Survey, 59, cisgender man, gay, prostate)

Incontinence also meant having to “change my clothes . . . if I started sneezing,” and as a result you “live walking on eggshells all the time because you don’t know what’s going to happen”<sup>r</sup> (Fredrick, 57, cisgender man, gay, prostate).

For some, post-surgical scarring resulted in feeling “self-conscious”<sup>st</sup>. As a survey participant told us: “I am very conscious of the skin lesions, more so being gay I think”<sup>t</sup> (Survey, 67, cisgender man, gay, medical intervention). For gay men, scars were reported to have the potential to “ruin . . . prospects at a sex venue”<sup>uu</sup>. Breast reconstruction scars that look as if “somebody’s chopped your breast off” could negatively “affect self-image”<sup>vv</sup> (Teresa, 55, cisgender woman, lesbian, breast). However, others were not troubled by scarring, with one participant saying, “I didn’t care that I had a 20 centimeter scar, that didn’t actually worry me that much”<sup>ww</sup> (Paulette, 67, cisgender woman, lesbian, bowel), explaining, “Some people

deal with that better than others depending on their own self-image in their own self . . . and I think that also is something for lesbians maybe<sup>w</sup>. Conversely, having a stoma, described as “pretty hideous<sup>x</sup> and “very embarrassing<sup>y</sup>, was reported by some to have “made me feel pretty weird about my own body and myself as a sexual being<sup>x</sup> (Sabrina, 53, cisgender woman, lesbian, ovarian), and “killed off my sex drive<sup>z</sup>, leading to “no desire to be intimate or even naked<sup>z</sup> (Survey, 43, cisgender man, gay, bowel) with potential or current sexual partners.

Being “sentenced to early menopause<sup>aa</sup> as a result of cancer treatment meant that some participants “lost all sex drive<sup>aa</sup> and experienced pain or discomfort associated with “vaginal walls (that) have collapsed<sup>aa</sup> (Virginia, 48, cisgender woman, lesbian, lymphoma). Others described being “painfully dry in my vagina and between my labia<sup>bb</sup> (Survey, 55, cisgender woman, pansexual, breast) and “fragile skin<sup>cc,dd</sup>, around the vulva that led to tearing. This led to some partners being “concerned about touching me because she’s very worried about hurting me” and “really hesitant about sex<sup>dd</sup> (Patricia, 65, cisgender woman, lesbian, uterine). Others described avoiding previously pleasurable penetrative sex.

I would once have really enjoyed penetration and now I get really nervous about penetration. And so now I can take a finger or two, but I certainly couldn’t take a dildo anymore, which is disappointing because I used to really enjoy that. I used to really enjoy a very uninhibited creative varied sex life. And so, it’s kind of it’s made it all just a little bit more precarious, more need to think things through and to have the lube available and so it’s a little bit less spontaneous. (Rita, PWC, 61, CF, Les, Cervical)

These physical changes sometimes served to challenge one’s identity as a LGBTQI person. Some participants described isolation in relation to queer communities because of a sense of disembodiment, leading to feeling “broken and disconnected” from LGBTQI “sex cultures<sup>ee</sup>:

Constant struggle to not feel broken and disconnected from the wonderful sex cultures I used to be such a big part of. It contributes to the sense of cultural/social isolation AND the sense of not-belonging in my own body. A lack of connection to my body and to other people – it’s a unique form of grief and I wish I had a space to talk to other queer people about it more. (Survey, 38, queer femme, medical intervention)

Lack of “sex drive and ability for romantic attraction” led to discomfort about feeling “more straight<sup>ff</sup>, because same-gender sexual attraction was central to LGBTQI identities. Loss of reproductive body parts, representing “all the things about me that are feminine<sup>gg</sup> led to questions “around gender and sexuality and who am I?”<sup>gg</sup> (Sabrina,

53, cisgender woman, lesbian, ovarian), as an altered body was at odds with one’s sense of self as a gendered being, a sexual being, and a lesbian. This was described as a “horrible” experience (Sabrina). This threat to identities was rarely acknowledged by others: “I really don’t think people understand the personal, symbolic and political implications for gay men when it comes to sex” (Survey, 50, cisgender gay man, prostate). Facial hair was a signifier of masculinity and gay identity, and loss of “beard hair<sup>hh</sup> following hormone therapy served to undermine the identities of trans men:

There was no support, recognition or understanding of the impact of losing the beard hair being a transman. I had to sit across from women getting fussed over and getting head cool pack things to try to stop their hair loss. There was no recognition or help for my loss, so linked to my identity. (Scott, 55, trans man, asexual, multiple cancers)

Gay men who identify as “bears<sup>ii</sup> also reported distress at loss of facial hair: “I also can’t grow my beard back properly since I’ve been on hormone therapy; which, as a ‘bear,’ is very important; indeed, I miss it very much” (Survey, 55, cisgender man, gay, prostate). These threats to LGBTQI identities represent negative impacts of cancer unique to this population and are rarely acknowledged.

### Coping with the Impact of Cancer on Sexual Well-Being

The third aim of the study was to identify coping mechanisms employed by LGBTQI people with cancer as they managed sexual changes and to determine whether coping was associated with sexual well-being or impacted by gender. The most used strategy for coping with sexual concerns was looking up information on the internet, which was pursued by 63% of participants ( $n = 203$ ). This was followed by talking to a healthcare professional ( $n = 163$ ; 50%), using sex aids ( $n = 158$ ; 49%), changing sexual practices ( $n = 139$ ; 43%), seeking counseling ( $n = 128$ ; 40%), medical intervention ( $n = 109$ ; 34%), and support groups ( $n = 106$ ; 33%). Independent samples  $t$ -tests indicated that three of the seven coping strategies were associated with differences in post-cancer sexual well-being (see Table 8). People who used support groups, looked up information on the internet, and sought counseling reported lower post-cancer sexual well-being than individuals who did not use these coping mechanisms.

Chi-square frequency tests for each coping mechanism indicated that the use of the mechanisms varied significantly

**Table 8.** Sexual well-being post-cancer by coping strategy use.

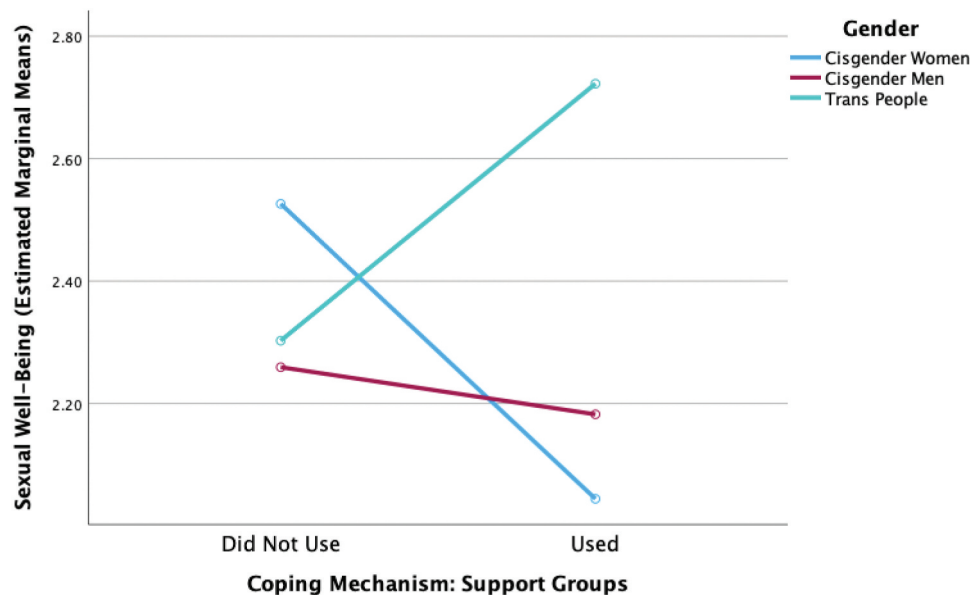
	$r$	$p$ (correlation)	$t(df)$	$p$ ( $t$ -test)	$M (SD)$	
					Did Not Use	Used
Talking to a Healthcare Professional	.39	<.001	.88(274)	.38	2.40 (.87)	2.31(.90)
Support Groups	.08	.45	1.96(274)	.05	2.42(.89)	2.20(.86)
Looking Up Info on the Internet	.18	.01	2.85(274)	.01	2.55(.87)	2.24(.88)
Counseling	.08	.39	3.22(273)	.001	2.49(.85)	2.15(.90)
Changing Sexual Practices	.44	<.001	.75(271)	.45	2.39(.93)	2.31(.83)
Medical Intervention	.45	<.001	.90(273)	.37	2.38(.88)	2.28(.90)
Sex Aids	.43	<.001	.89(275)	.38	2.40(.90)	2.30(.87)

$r$  = correlation between strategy use and sexual well-being.

**Table 9.** Coping mechanism frequencies by gender.

Coping Mechanism	$\chi^2$	<i>p</i>	Used <i>n</i> (% of gender)			Not Used <i>n</i> (% of gender)		
			Cisgender Women	Cisgender Men	Trans People	Cisgender Women	Cisgender Men	Trans People
Talking to a HCP	26.90	<.001	61 (36.7%)	76 (68.5%)	23 (52.3%)	105 (63.3%)	35 (31.5%)	21 (47.7%)
Support Groups	19.05	<.001	36 (22.1%)	52 (47.3%)	15 (34.1%)	127 (77.9%)	58 (52.7%)	29 (65.9%)
Looking Up Info on the Internet	23.62	<.001	83 (50.3%)	88 (79.3%)	27 (61.4%)	82 (49.7%)	23 (20.7%)	17 (38.6%)
Counseling	10.52	.005	50 (30.5%)	55 (49.5%)	19 (43.2%)	114 (69.5%)	56 (50.5%)	25 (56.8%)
Changing Sexual Practices	6.87	.032	58 (35.6%)	55 (49.1%)	22 (52.4%)	105 (64.4%)	57 (50.9%)	20 (57.6%)
Medical Intervention	25.16	<.001	35 (21.2%)	56 (50.0%)	16 (37.2%)	130 (78.8%)	56 (50.0%)	27 (62.8%)
Sex Aids	4.50	.11	72 (43.4%)	63 (56.3%)	20 (46.5)	94 (56.5%)	49 (43.8%)	23 (53.5%)

Calculations are based on participants who indicated that they did use or did not use a coping mechanism. Percentages do not include missing responses/participants who chose not to respond.

**Figure 2.** Interaction of time (pre- to post-cancer) and gender on sexual well-being post-cancer.

by gender, except for the use of sexual aids. The full results are reported in Table 9. In general, cisgender men reported the highest use of each coping strategy, except for changing sexual practices, which trans people used the most. Additionally, a series of two-way ANOVAs with gender and coping mechanism (used/not used; each mechanism was tested in a separate model) as fixed factors predicting post-cancer sexual well-being indicated that only the use of support groups interacted with gender to predict sexual well-being,  $F(2, 266) = 3.54$ ,  $p = .03$ . Trans people who used support groups as a coping mechanism reported higher post-cancer sexual well-being than those who did not attend support groups (see Figure 2). In contrast, cisgender people who did not use support groups reported higher sexual well-being than those who did use support groups.

Bivariate correlations examined if the perceived helpfulness of the coping mechanism was associated with sexual well-being. The analysis focused only on individuals who indicated

using the coping mechanism in question. The more individuals reported that talking to healthcare professionals, looking up information on the internet, changing sexual practices, medical interventions, and using sexual aids were helpful in addressing their sexual concerns, the greater their post-cancer sexual well-being. In contrast, the extent to which support groups and counseling were reported as helpful was not significantly associated with post-cancer sexual well-being (see Table 9).

### **Renegotiating Sex and Intimacy: Coping with Sexual Changes**

The qualitative analyses identified a diverse range of experiences of coping with sexual changes (see Supplementary Table S5). Several participants reported seeking help. Seeing a psychologist was described as having “helped our relationship a lot,” in particular “helping communication”<sup>11</sup> (Beth, 59, cisgender woman, lesbian, brain). However, a cisgender gay male



survey participant (59, prostate) reported that it had been “very difficult to find a psychologist”<sup>kk</sup> when feeling “suicidal” following erectile dysfunction and loss of ejaculate. Another participant reported engaging “the assistance of a sex worker” with expertise in “helping people with disability have sex”<sup>ll</sup> (Survey, 55, cisgender man, gay, prostate).

Cancer related sexual changes were described by some as having “made me explore a lot about myself” (Leonard, 58, cisgender man, gay, prostate), including “embrace more of the sexual side of it, exploring things I haven’t done” (Jake, 30, cisgender man, gay, testicular). Renegotiated sexual intimacy included mutual masturbation, which was described as being “part of our relationship, really”<sup>mm</sup> (Archer, 59, cisgender woman, lesbian, bowel), and “being a lot more sexually open” through exploring “hard kinks,” such as “fisting,” “watersports” and being “vers” (versatile) in relation to anal sex<sup>nn</sup> (Jake, 30, cisgender man, gay, testicular). Some participants said renegotiated sex was a “positive experience”<sup>nn</sup>, that they felt “sexier after cancer than before” (Survey, 56, queer woman, uterine cancer), or that cancer “made us talk about so much STUFF that we did sex and orgasms and bodily intimacy brilliantly” (Survey, 52, queer, transman, thyroid cancer), even though things were “different.” Another said:

Not having a clitoris is a huge thing but we’ve worked around that. So, things are different. We still have an awesome sex life, but it’s not what it was. But that is changing and evolving too. (Catherine, 61, cisgender woman, bisexual, vulval)

“The way that lesbians have sex”<sup>oo</sup> was provided as an explanation for continued sexual engagement post-cancer, in contrast to heterosex, where “if I had a male partner with my painful vagina I wouldn’t be able to have sex with him and that would be very difficult”<sup>oo</sup> (Martha, 48, cisgender woman, lesbian, bowel). Focusing on “physical, emotional intimacy,” including “cuddling,” “walking around naked in front of each other,” and “intimate language”<sup>pp</sup> (Ryan, 60, cisgender man, gay, prostate) was the new sexual normal for some. As Sabrina told us, “I love her skin; we both love each other’s skin. It’s that good old definition of ‘what’s sex?’ We haven’t lost that throughout this whole process” (53, cisgender woman, lesbian, ovarian). The “physical cuddling and hugging and other intimacies” were described as “very satisfying” (Survey, 73, lesbian woman, breast cancer). For other individuals, there was “no shame in using interventions, aids, prosthetics and anything else that is legal and consenting”<sup>qq</sup> (Survey, 52, trans man, queer, thyroid), or lubricants: “I’m 61 so if I haven’t heard of lube by now, having been out as queer and lesbian since I was 14 or 15. I didn’t need to find it especially”<sup>rr</sup> (Rita, 61, cisgender woman, lesbian, cervical). Sex aids were sometimes effective, leading to a “sex life that is 100% better”<sup>qq</sup>, particularly in relation to penile injections, which “once you get the dosage right, . . . work all the time”<sup>ss</sup> (Billy, 67, cisgender man, gay, prostate). However, other participants described penis injections as abhorrent<sup>tt</sup>:

No, thank you. It doesn’t really appeal. However small the needle might be and however you might tell me I won’t feel it, it just doesn’t seem like a very nice or very natural thing to do. (Matthew, 57, cisgender man, gay, prostate)

Equally, several participants rejected the use of vaginal expanders, “because it felt too clinical”<sup>rr</sup> or reported that “the pills don’t work”<sup>ss,uu</sup>, and served to “take away spontaneity”<sup>vv</sup>. Medical aids were therefore not the solution to sexual changes that many hoped they would be.

## Discussion

A robust body of literature indicates that sexual well-being is negatively impacted by cancer and its treatment (Olesen et al., 2023; Perz et al., 2014; Seguin et al., 2020), leading to calls for healthcare practitioners to provide information and supportive interventions to facilitate coping and ameliorate associated distress (Schubach et al., 2023; Ussher et al., 2020). Our results confirm that sexual well-being is also an area of concern for LGBTQI people with cancer (Kokay et al., 2023; McInnis & Pukall, 2020; Rodrigues et al., 2023). Among diverse gender and sexual identities, age groups, and cancer types, we found that sexual well-being decreased from pre- to post-cancer, both when examining overall sexual well-being and specific facets such as sexual desire and enjoyment of sexual activity. Prior research in the non-LGBTQI cancer population indicated that a range of psychological (Frankland et al., 2020; Perz et al., 2014; Seguin et al., 2020), social and relational (Benoot et al., 2017; Castro et al., 2023; Collaço et al., 2018), and physical (Carter et al., 2013; Galbraith & Crighton, 2008) factors were associated with sexual well-being. Our study confirms that this is also the case for LGBTQI people with cancer, with greater social and relational support, fewer physical concerns, and greater QOL associated with greater post-cancer sexual well-being.

The limited previous research on LGBTQI people’s experiences of post-cancer sexual well-being suggested that there may be differences between genders. Our analyses revealed that, although post-cancer sexual well-being did not vary by gender, *changes* in sexual well-being did vary significantly, with cisgender GBM experiencing the sharpest declines from pre- to post-cancer. This can partially be explained by the higher levels of pre-cancer sexual well-being reported by GBM, reflecting the importance of sexual functioning in many GBM’s relationships (Dowsett, 1993; Halperin, 2007). Prior work suggests that cancer’s impact on sexual well-being may be especially difficult for GBM (McInnis & Pukall, 2020; Rosser et al., 2016; Wassersug et al., 2013) due to the impact of sexual dysfunction and other embodied changes on gay male sexual subjectivity, leading to a sense of sexual disqualification. In contrast, it has been argued that less emphasis is placed on sex in lesbian relationships (Arena et al., 2007), with sexual intimacy often decreasing in long-term relationships, a phenomenon described as “lesbian bed death” (Diamond, 2015; van Rosmalen-Nooijens et al., 2008). This may explain the lesser magnitude of pre-post cancer sexual changes in lesbians in comparison with GBM. However, there is also evidence that sexual intimacy is maintained in the long-term relationships of sexual minority women, including the use of lubricants to facilitate penetration, and satisfaction associated with non-penetrative sexual practices (Cohen & Byers, 2014). This confirms qualitative findings in the present study and previous reports that lesbians reported limited disruption from post-



cancer sexual changes, compared with cisgender heterosexual women (Ussher et al., 2014). In our study, trans people experienced the least amount of sexual change, which may reflect findings that for some trans individuals, cancer treatment can affirm gendered embodiment (Alpert et al., 2021; Ussher, Power, et al., 2023), with positive consequences for sexual well-being. There is a need for further research on the post-cancer sexual well-being of trans people, as well as those with intersex variations – populations whose experiences are under-explored in LGBTQI cancer research (Alpert et al., 2021; Kokay et al., 2023; Ussher et al., 2024).

There were some gender differences in rates of physical change, linked to the impact of specific cancer types on the body (e.g., breast and uterine cancer for cisgender women and trans people with a cervix; prostate cancer for cisgender men and trans people with a penis). Participant reports of the subjective impact of these physical changes, in terms of distress and relational disruption, are analogous to those found in the general cancer population (e.g. Benoot et al., 2017; Collaço et al., 2018; Gilbert et al., 2011; Seguin et al., 2020). However, in some instances, the meaning of physical changes for LGBTQI people may be different, reflected in qualitative accounts in the present study. Previous research has reported that GBM are more likely than heterosexual men to report distress at reduced penis size and loss of ejaculate following cancer treatment (Ussher et al., 2016), due to the importance of penis size in gay male sex and the meaning of ejaculation, including “cum,” as a visible signifier of sexual pleasure (McInnis & Pukall, 2020; Ussher et al., 2017). The focus on “body beautiful” for GBM (Levesque & Vichesky, 2006), reflected in higher rates of body dissatisfaction in comparison with heterosexual men and lesbian women (Morrison et al., 2004), may influence GBM’s responses to having a stoma and experiencing loss of muscle mass following cancer treatment. Breast changes and mastectomy may have a negative impact on LGBTQI patients (Skorzewska et al., 2021); however, some LGBTQI patients forego breast reconstruction after mastectomy and embrace “going flat” (Brown & McElroy, 2018; Rubin & Tanenbaum, 2011; Wandrey et al., 2016) in order to facilitate an alignment between gender identity and embodiment (Taylor & Bryson, 2016). Equally, although some lesbian, bisexual, and queer women may be able to adapt to post-cancer vaginal dryness (Ussher et al., 2014) due to the absence of heteronormative sexual scripts that focus on penetrative sex (Gabb, 2019), others experience distress and relationship disruption associated with post-cancer vaginal changes (Rodrigues et al., 2023). These physical changes can have a negative impact on embodiment and a sense of self, undermining trans, queer, and bisexual identities, with detrimental consequences for well-being. When providing information and healthcare, it is essential that healthcare professionals (HCPs) openly discuss the impact and meaning of physical changes on sexual well-being for each patient without making assumptions based on gender identity and expression or sexual orientation. At the same time, HCPs need to be aware of the unique impact of physical and sexual changes for LGBTQI people in order to facilitate coping with sexual changes (Quinn et al., 2020; Rodrigues et al., 2023; Ussher, Power et al., 2022).

The perceived helpfulness of utilized coping mechanisms was associated with greater sexual well-being across the sample, with cisgender men reporting the highest frequencies for all coping mechanisms. This confirms previous reports of GBM having higher rates of coping with post-cancer sexual changes through seeking information, healthcare support, and use of medical and sexual aids, compared with heterosexual men (Ussher et al., 2019). However, medical aids were not always effective, as reported previously (Ussher et al., 2019), and can lead to avoidance of sex. Across all groups, searching for information online was the most frequently used coping mechanism, as reported in previous research with GBM (Ussher et al., 2019), with support groups and counseling the most under-utilized. LGBTQI people were more likely to seek information online, and to eschew cancer support groups or counseling due to fear of discrimination, privacy concerns, and avoidance of distress associated with the disclosure of LGBTQI identities to HCPs (Ussher, Power et al., 2022). In the present study, people who looked up information online, used support groups, or sought counseling reported lower post-cancer sexual well-being than individuals who did not use these mechanisms. It may be the case that individuals who are experiencing lower sexual well-being are more likely to utilize these coping mechanisms. The lower rates of sexual well-being may also result from support needs not being met when LGBTQI people seek help, as the majority of online cancer support information does not include any mention of LGBTQI people or their relationships (Ussher, Ryan, et al., 2023), and LGBTQI people often report hostility and prejudice on the part of HCPs and support group members (Ussher, Power et al., 2022). There is a need for cancer organizations to be LGBTQI inclusive within general cancer information and to provide LGBTQI-tailored patient information that addresses the unique needs of different LGBTQI subpopulations, in order to improve the cultural safety of LGBTQI patients and their partners (Pratt-Chapman et al., 2022; Ussher, Ryan, et al., 2023). Our finding that trans people who used support groups as a coping mechanism reported higher post-cancer sexual well-being than those who did not attend support groups, could be because cisgender people have greater informal support from friends and family, and trans people may experience marginalization in the LGBQ community (Closson & Comeau, 2021), leading to greater need for support groups.

Across the sample, supportive communication, particularly from sexual partners, emerged as an especially meaningful way to cope with cancer-related sexual changes and the emotions that accompany them, which has also been reported in previous research in the general cancer population (Gorman et al., 2020; Liberacka-Dwojak & Izdebski, 2021; Perz et al., 2014; Traa et al., 2015). In the interviews, participants emphasized the importance of open communication and partner support and acceptance in maintaining sexual well-being, confirming the value of a dyadic approach to coping with post-cancer sexual changes. Communication was also central to the renegotiation of sex after cancer, including non-genital intimacy such as kissing and touching, and new forms of genital sex, as reported previously (Ussher, Perz, Gilbert, Wong, et al., 2013). Supportive communication has many benefits for individual, relational, and physical health (MacGeorge et al., 2011), and such benefits clearly transfer to the context of managing cancer-related sexual

changes (Perz et al., 2014). Together, these findings have valuable implications for patients and HCPs in arguing that LGBTQI people with cancer should be encouraged to acknowledge and discuss the impact of cancer on their sexual embodiment and relationships in order to facilitate sexual renegotiation (Barsky et al., 2006). LGBTQI people might also be encouraged and assisted to marshal support from partners and close others, given the benefits of such support in managing the psychological and physical toll of cancer (Kahana et al., 2009; Traa et al., 2015). Sexuality and identities are generally openly discussed within intimate LGBTQI relationships (Kattari, 2015), which may serve to support and enhance this communication, leading to a greater likelihood of sexual renegotiation and associated positive health outcomes (Dowsett et al., 2014; Ussher et al., 2019).

### Strengths and Limitations

There were several strengths and limitations to this study. The strengths were the diverse sample, inclusive of a range of sexual and gender identities, cancer types, and age groups. The use of a mixed-methods approach was also a strength. A limitation was the cross-sectional nature of the data, with pre-cancer sexual well-being assessed retrospectively. Longitudinal work that follows LGBTQI patients from diagnosis to treatment and recovery is needed to understand in more depth not only sexual health among this vulnerable population, but also a variety of cancer-related experiences that are absent or under-examined in the literature.

### Conclusion

The findings of this study confirm that changes in post-cancer sexual well-being are an area of concern for LGBTQI people with cancer. Addressing these concerns is a matter of sexual and reproductive justice (Morison, 2023) for a marginalized group of cancer patients whose needs are often overlooked within cancer care (Quinn et al., 2015). Sexual well-being should be acknowledged and addressed by HCPs working with LGBTQI people with cancer (Rodrigues et al., 2023). Supportive care models such as PLISSIT (Annon, 1981) and BETTER (Mick et al., 2004), which are widely adopted to address sexual well-being in the general cancer population (Ussher et al., 2020), are relevant for understanding and ameliorating sexual changes for the LGBTQI population. However, it is essential that HCPs adapt these models within a framework of inclusive and culturally safe cancer care (Pratt-Chapman et al., 2022; Quinn et al., 2020), which acknowledges sexuality and gender diversity, the unique sexual needs and experiences of this patient group, and includes same-gender and trans partners, and other chosen family, in consultations.

Following the PLISSIT model, HCPs need to acknowledge and address sexual well-being through providing permission for LGBTQI patients and their partners to discuss sexual concerns, providing LGBTQI inclusive information about sexual changes and their causes (e.g. Cancer Council Australia, 2015, 2023), providing information on strategies for coping, and referring patients for specific sexual therapy, if required (Ussher et al., 2020). However, many oncology

HCPs express a lack of knowledge and confidence in working with LGBTQI patients (Schabath et al., 2019; Tamargo et al., 2022; Ussher, Perz, et al., 2022), in particular when addressing sexual well-being concerns (Ussher, Perz, Gilbert, Wong, et al., 2013). At a systems level, clinical management teams need to acknowledge the importance of addressing the needs of LGBTQI patients and support the development of HCP communicative competence (Maguire & Pitceathly, 2002) to address gaps in knowledge and confidence on the part of HCPs (Pratt-Chapman et al., 2022; Ussher, Perz, et al., 2022). Specific training in inclusive cancer care as part of basic communication training and ongoing professional development is essential (Pratt-Chapman, 2021; Quinn et al., 2020). Such programs can increase HCP knowledge and confidence, challenge misconceptions about LGBTQI sexuality, and increase the likelihood of LGBTQI patients receiving inclusive and affirmative information and support to address their sexual needs and concerns. Together, recognizing and supporting the needs and concerns of LGBTQI cancer patients can assist in the challenging task of (re)negotiating sexuality after cancer and contribute to LGBTQI people's sexual and general well-being.

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### ORCID

Jane M. Ussher  <http://orcid.org/0000-0002-2128-0019>

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