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Care for sexual health in oncology survey: Discussions about sexual health with people with cancer in the context of the obligation to provide informed consent

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ABSTRACT

Purpose: The purpose of this paper is to describe the impacts of cancer treatment on sexual health in a sample of people who had been treated for mixed types of cancer; to describe discussions they had with professionals about sexual health that occurred during cancer care; and to consider the extent to which these discussions were sufficient to enable participants to give informed consent for the sexual side effect of cancer treatment.

Method: A cross-sectional, online survey using a convenience sample of people with cancer was recruited via UK cancer charities. Eligibility criteria included having received treatment and follow-up care for any type of cancer in the UK during the previous 10 years. Univariate analysis was conducted using SPSS.

Results: 136 people with cancer participated in this survey. The majority of participants reported having experienced a worsening of their sexual lives, which bothered them. Whilst 33.6% of the sample (n = 125) reported having discussed sexual health during their cancer care, only 5.4% reported that a healthcare professional initiated a pre-treatment discussion about the sexual side effects of cancer treatment.

Conclusions: These results suggest that the proportion of participants who were provided with sufficient information to give informed consent for the sexual side effects of cancer treatment was very low. This indicates that healthcare professionals may require specific advice on how to include this topic during the informed consent process.

1. Introduction

1.1. Background/rationale

In 2006, the World Health Organisation (WHO) (2022) defined sexual health in an holistic manner. This definition is consistent with a biopsychosocial approach to healthcare and is provided below:

> “Sexual health: a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive, respectful approach to sexuality and sexual relationships and the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled”.
>
> (WHO, 2024a)

Both current and historic reviews on the sexual health of people with cancer have shown that sexual health difficulties after cancer treatment are both manifold and frequently experienced (Bober and Varela, 2012; Jing et al., 2019; Priviero and Webb, 2022; Sanchez Varela et al., 2013), according to, for example, tumour site and sex/gender. Reese et al. (2017) noted that the sex-related sequelae are amongst the most frequent, distressing, and persistent consequences of cancer treatment. Much of the research on sexual health following cancer treatment

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has focussed on the biological impacts of cancer treatment in terms of sexual dysfunction specifically. Examples include, lack of desire and difficulties with arousal having been found in both males and females with different types of cancer (Traa et al., 2012; Lammerink et al., 2012; Runowicz et al., 2016; Cancer Research UK no date). Furthermore, females have also reported dyspareunia (Traa et al., 2012; Runowicz et al., 2016). Although research has largely focussed on the biological impacts on sexual health, psychosocial impacts have also been reported. Examples of psychological impacts of cancer treatment on sexual health that have been reported include negative effects on body image in breast cancer (Runowicz et al., 2016), gynaecological cancer (Wilson et al., 2021), prostate cancer (Bowie et al., 2021), and colorectal cancer (Stulz et al., 2020). Other psychological impacts include sexual distress (Walker et al., 2021) and depression (Ussher et al., 2012). Additionally, interpersonal sex-related sequelae of cancer treatment have also been reported, such as relationship discord (Rowland and Metcalfe, 2014) and fear of intimacy (Ussher et al., 2012).

Despite the above impacts on sexual health, people with cancer continue to report that sexual health was not discussed during their cancer journey (Zhang et al., 2020). This is despite the availability of numerous biopsychosocial treatment options (Sopfe et al., 2021) and a variety of theoretical frameworks to help healthcare professionals (HCPs) discuss sexual health (Annon, 1976 in Sanchez Varela et al., 2013; Mick et al., 2004; Taylor and Davis, 2007; Park et al., 2009; McCaughan et al., 2020). Lack of discussion about sexual health during cancer care (Zhang et al., 2020) may impede the care provided for sexual health difficulties. Specifically, lack of discussion tends to result in patients consenting to treatments with inadequate information about their potential consequences. To the extent that enabling informed consent is a key responsibility of healthcare professionals, this is a troubling aspect of current approaches to sexual health.

Much is already known about the barriers to sexual health communication (Canzona et al., 2019; Zhang et al., 2020). In 2009, Park et al. reviewed the literature on sexual health communication in cancer care and noted many factors that hindered sexual health discussions. Examples of barriers perceived by patients to their receiving care included patients needing HCPs to raise the topic. Additionally, patients holding erroneous beliefs about cancer and sex were also considered to inhibit discussion. An example of such a belief was 'being able to catch cancer through having sex' (Perz et al., 2013). Examples of barriers to providing care from HCPs' perspectives included staff being inhibited by certain patient demographics/clinical characteristics, by personal discomfort with the topic, and by a lack of training. In a more recent scoping review on the same topic, Zhang et al. (2020) found similar barriers to those described by Park et al., in 2009.

With a view to further improving the care for sexual health in people with cancer, an online survey was conducted in the UK. This survey was the first part of an overall mixed methods project, which related to the barriers to and facilitators of care for sexual health in UK hospital cancer care. This survey was conducted to provide broad information, as reported by people with cancer, about both their sexual health and their experiences of care for their sexual health. For clarification, inferential statistics related to survey findings have not yet been reported. The focus of this paper is to report on findings related to discussions about sexual health in cancer care.

1.2. *Objectives*

To describe:

1. The impact of cancer and its treatment on the sexual health of people with cancer in the UK.
2. People with cancer's self-reporting on the nature of discussions with the UK hospital cancer team about sexual health, and the proportion of those reporting different types of discussions.
3. The estimated proportion of people with cancer providing informed consent for the sexual side effects of cancer treatment.

2. Methods

2.1. *Study design*

The study design was a cross-sectional, anonymous, online survey with both open and closed question types.

2.2. *Setting/participants*

A convenience sample was recruited via the social media channels and websites of 20 UK cancer charities (which included most types of cancer). Participants identified themselves via adverts placed by cancer charities, and provided confirmation of eligibility and informed consent via the online survey system before completing the survey. The survey was open to recruitment between 23rd August 2022 and 30th September 2022. Eligibility criteria included: a) people with any type of cancer who were partnered or single; b) cancer diagnosis at age 18 years or over; c) cancer diagnosis up to 10 years ago; d) cancer treatment and follow up must have been in the UK. Due to the sensitive nature of the topic, a link to a help and support page was available to participants on each page of the survey.

2.3. *Variables/data sources/measurement*

Jisc Online Surveys was used to design, display and collect data (Online Surveys, 2022), which was retrospectively self-reported by participants. The principles of general survey development were considered and applied to the design of this survey (Fink, 2016; McColl et al., 2001; Mathers et al., 2007). The survey was composed of seven sections (see supplementary data file 1) and was designed following literature reviews on cancer and sexual health, and with the help of a local patient and public involvement and engagement (PPIE) group. PPIE involvement in survey design clarified that the topic of interest should be described as sexual health/wellbeing rather than sexual health only. The addition of the term 'wellbeing' was partly to mitigate the risk of participants equating sexual health with sexually transmitted infections. From the research team's perspective, the term 'sexual wellbeing' alone was not used because there remains a lack of consensus around the definition for the concept of 'sexual wellbeing' (Lorimer et al., 2019). The focus of the survey is sexual health and sexual activity plus the care for these aspects of life. WHO (2024) do not define the word wellbeing in their definition of sexual health and therefore the United Kingdom Department of Health's (2014) definition has been chosen to define this term, which is "wellbeing is feeling good and functioning well".

Four out of seven sections of the survey have been reported here, and these are described next.

Section 1 contained variables relating to individuals' cancer characteristics including their cancer type, cancer stage, time since diagnosis, previous treatments and whether currently receiving treatment. These variables were selected based on findings from the literature reviews on cancer and sexual health.

Section 2 contained variables on sexual activity and used selected questions from the validated Sexual Function Questionnaire (SFQ) and its associated Health Impact Scale version 2017 that was originally developed by Syrjala et al., in 1998 (Syrjala et al., 2000; Syrjala et al., 2000 unpublished manual). Permission was received from the Fred Hutchinson Cancer Research Centre in the USA to use the aforementioned questions. The SFQ instructions were also used in order to improve self-reporting, as recommended by Syrjala et al. (2000). The SFQ was selected because it can be used by males and females (no participants reported other sexual designations), does not depend on an individual being sexually active and explores treatment impact. Because the overarching focus of this study was on care, rather than sexual activity, combined with a concern that the time required to respond to all the included instruments in full would be overly burdensome for participants, the full SFQ was not used. SFQ variables included: 1) sexual activity in the past year; 2) sexual activity in the past month; 3) reasons for sexual inactivity; 4) impact of cancer/cancer treatment on sex life. Researcher generated statements included: 1) to what extent to do you agree with the statement 'the changes to my sex life bother me'; 2) type of sexual activity engaged in during past year; plus 3) four statements that were generated from a preliminary literature review about sexual health following cancer/cancer treatment. These statements related to sexual confidence, relationship difficulties and being single (participants were given the opportunity to state their level of agreement on a 5-point Likert scale). The qualitative results were generated via an optional, open-ended question from the long version of the SFQ, which provided an opportunity for participants to give more details on how sex had changed for them since their illness/treatment, these results are reported herein.

Section 4 related to the care for sexual health received by participants from the UK hospital cancer team following cancer and its treatments. No validated questionnaire was available on this topic and therefore following a review of various frameworks aimed at enabling this type of care including PLISSIT (Annon, 1976 in Sanchez Varela et al., 2013), BETTER (Mick et al., 2004), EX-PLISSIT (Taylor and Davis, 2007), 5 As (Park et al., 2009) and EASSi (McCaughan et al., 2020), it was decided to structure these variables in terms of the main points of care including: discussing, assessing, providing information and advising/treating sexual health concerns. However, only data related to discussing sexual health are presented in this paper. The initial variable in this section was 'did the hospital cancer team ever talk about sexual health/wellbeing at any time during cancer care?' (see limitations section for attempts to improve validity for this initial variable).

Sociodemographic characteristics were collected in section 7 and were based on the UK Census 2021 for ethnicity, sex, gender and sexual orientation (Office for National Statistics, 2021, 2022). Other sociodemographic characteristics included age, partnership status and highest level of education achieved, these were collected due to perceived importance in similar studies.

2.4. *Study size*

While this paper reports on the descriptive statistics of this survey, the study was powered to enable regression analysis. Following Long's (1997) recommendation that at least ten observations per parameter/variable are required for most regression models with categorical variables, a sample size of 120 was selected to allow for the inclusion of up to 12 categorical parameters/variables. No maximum sample size was considered necessary because greater numbers were anticipated to improve the precision of the quantitative results.

2.5. *Statistical/analytical methods*

Closed question type variables were analysed using descriptive statistics with frequencies and percentages calculated by SPSS version 28 (IBM Corp, 2021). Missing data was minimised through study design, as all questions required a response in the online survey system with additional options of 'I prefer not to say' or 'I cannot remember' enabling this.

Open ended question type variables were analysed using reflexive thematic analysis (Braun and Clarke, 2006, 2022) to show how people's sexual lives have been impacted by cancer treatment. These included both responses to the open-ended question which offered the opportunity to provide details about how sex had changed since their illness/treatment, and also responses in other parts of the survey where participants commented about how their sexual lives had changed. Following familiarisation with the data, a deductive approach was taken with responses categorised into biological, psychological and social changes. The biological category was further sub-divided into responses relating to the major categories of sexual dysfunction (i.e. desire, arousal, orgasm and pain) or those related to other issues. An additional category was also created for comments specifically related to changes in people's sex lives in terms of quantity and quality of sexual activity. Deductive categorisation was followed by inductive coding of the data and generation of themes. Participants' responses were coded by one researcher (SS). Coding and theme development were triangulated by two co-authors (SP and SL).

2.6. *Ethics*

The study was approved by Bournemouth University's Science, Technology and Health Research Ethics Panel in July 2022 (Ethics identification number 39453). This study was retrospectively registered with clinicaltrials.gov and the unique identifying number is: NCT06074445. Additionally, this study has been added to the UK, National Institute of Health Research, Clinical Research Network, Portfolio of Studies (CPMS ID 52741).

2.7. *Reporting*

The STROBE checklist for cross-sectional studies was adhered to for reporting purposes (von Elm, 2008).

3. Results

3.1. *Participants*

One hundred and thirty-six people with cancer completed the survey. Unfortunately, a precise completion rate as a percentage of those who commenced the survey is not available because 33 partners of people with cancer also completed the survey and it is not possible to disaggregate the two groups' completion rates. The completion rate for the total sample was 70%. Reasons for non-completion were not available.

The characteristics (sociodemographics, cancer characteristics and sexual activity) of the sample are described in Table 1 (column 2) for those participants with a valid response to the question 'did the hospital cancer team ever talk about sexual health/wellbeing' (n = 125). The purpose of describing this restricted sample, rather than the complete sample (n = 136), was to enable the nuanced characteristics of those who talked and did not talk to be displayed. In summary, participants were majority ≥50 years old (78.4%), female (61.3%), cis-gendered (61.3%), partnered (91.9%), white (96%), heterosexual (87.6%), and educated to a level greater than 18 years old (57.8%). The most common types of cancer that people were diagnosed with were haematology (32%), gynaecology (21.6%), genitorurinary (17.6%), gastrointestinal (10.4%) and breast (8%) with 10.4% of participants have being diagnosed with a variety of other types of cancer. Whilst, cancer stage at diagnosis (n = 94) was reported to be 46.8% for stages 1 & 2 and 53.2% for stages 3 & 4, many participants were not included in the analysis of this variable. This was because many participants were unsure of their cancer stage (n = 31). Although few participants were diagnosed less than 6 months prior to completing the survey (7.3%), participants from each of the other three time categories were similar in number. Chemotherapy was the most frequent treatment type (71.2%/n = 89), with 60% (n = 75) having received surgery, 30.4% (n = 38) having had radiotherapy, and 25.6% (n = 32) having had a stem cell/bone marrow transplant. Additionally, 50.4% of people were currently not receiving any cancer treatment.

As previously stated, Table 1 additionally provides descriptive statistics related to the variable that asked whether participants did and did not talk about sexual health with the hospital cancer team during their cancer journey. Out of the complete sample of 136 participants, 7 could not remember whether or not they had ever talked to the hospital cancer team about their sexual health/wellbeing. A further 4 participants were excluded from the analysis because whilst they had responded to the

Table 1
Characteristics of people with cancer who participated in an online, cross-sectional survey on care for sexual health in the UK.

SURVEY VARIABLES		Participants N (%)	Did not talk about sexual health N (%)	Did talk about sexual health N (%)
CARE FOR SEXUAL HEALTH				
Did the hospital cancer team ever talk about sexual health/wellbeing? (n = 136)		125[a] (91.9)	83 (66.4)	42 (33.6)
SOCIODEMOGRAPHICS				
Age (n = 125)	<50 years	27 (21.6)	18 (66.7)	9 (33.3)
	≥50 years	98 (78.4)	65 (66.3)	33 (33.7)
Sex at birth (n = 124)	Female	76 (61.3)	52 (68.4)	24 (31.6)
	Male	48 (38.7)	31 (64.6)	17 (35.4)
Ethnicity (n = 124)	White	119 (96.0)	79 (66.4)	40 (33.6)
	Other than white	5 (4.0)	4 (80.0)	1 (20.0)
Partnership status (n = 124)	Partnered (married/civil partnership/living together)	108 (87.1)	70 (64.8)	38 (35.2)
	Partnered but not living together	6 (4.8)	4 (66.7)	2 (33.3)
	Not partnered (e.g. divorced, separated/widowed/ never married)	10 (8.1)	8 (80.0)	2 (20.0)
Age when education was completed (n = 116)	≤18 years	49 (42.2)	35 (71.4)	14 (28.6)
	>18 years	67 (57.8)	43 (64.2)	24 (35.8)
Sexual Orientation (n = 121)	Heterosexual	106 (87.6)	69 (65.1)	37 (34.9)
	Non-heterosexual	15 (12.4)	11 (73.3)	4 (26.7)
CANCER CHARACTERISTICS				
Cancer type (n = 125)	Haematology	40 (32.0)	25 (62.5)	15 (37.5)
	Brain/Neurological	1 (0.8)	1 (100.0)	0 (0.0)
	Breast	10 (8.0)	8 (80.0)	2 (20.0)
	Gastrointestinal (upper and lower)	13 (10.4)	10 (76.9))	3 (23.1)
	Genitorurinary	22 (17.6)	10 (45.5)	12 (54.5)
	Gynaecological	27 (21.6)	18 (66.7)	9 (33.3)
	Head and Neck	2 (1.6)	2 (100.0)	0 (0.0)
	Lung	4 (3.2)	3 (75.0)	1 (25.0)
	Musculoskeletal	1 (0.8)	1 (100.0)	0 (0.0)
	Skin	5 (4.0)	5 (100.0)	0 (0.0)
	AIDS related; Endocrine; Eye; Cancer of unknown primary; Other	0 (0.0)	0 (0.0)	0 (0.0)
Cancer stage (n = 94[b])	Stages 1 & 2	44 (46.8)	31 (70.5)	13 (29.5)
	Stages 3 & 4	50 (53.2)	30 (60.0)	20 (40.0)
Time since diagnosis (n = 124)	≤6 months	9 (7.3)	4 (44.4)	5 (55.6)
	>6 months to < 2 years	35 (28.2)	23 (65.7)	12 (34.3)
	2 years–5 years	42 (33.9)	24 (57.1)	18 (42.9)
	>5 years to <10 years	38 (30.7)	31 (81.6)	7 (18.4)
Treatment ever received (n = 125): per participant agreement for each type of treatment	Surgery	75 (60.0)	53 (70.7)	22 (29.3)
	Chemotherapy	89 (71.2)	57(64.0)	32 (36.0)
	Radiotherapy	38 (30.4)	25 (65.8)	13 (34.2)
	Hormone Drug Therapy	16 (12.8)	11 (68.8)	5 (31.3)
	Targeted Cancer Drug	13 (10.4)	8 (61.5)	5 (38.5)
	Immunotherapy	25 20.0)	16 (64.0)	9 (36.0)
	Stem Cell or Bone Marrow Treatment	32 (25.6)	20 (62.5)	12 (37.5)
On cancer treatment now (n = 125)	No	63 (50.4)	44 (69.8)	19 (30.2)
	Yes	62 (49.6)	39 (62.9)	23 (37.1)
SEXUAL ACTIVITY				
Sexual activity in the past year (alone or with a partner) (n = 125)	No	39 (31.2)	32 (82.1)	7 (17.9)
	Yes	86 (68.8)	51 (59.3)	35 (40.7)
Sexual activity in the past month (alone or with a partner) (n = 86)	No	22 (25.6)	16 (72.7)	6 (27.3)
	Yes	64 (74.4)	35 (54.7)	29 (45.3)
Impact on sex life (n = 125)	My sex life is: as bad as it could be/a lot worse/a little worse than before cancer	106 (84.8)	72 (67.9)	34 (32.1)
	My sex life is: no different than before cancer/a little/a lot better than before cancer	19 (15.2)	11 (57.9)	8 (42.1)
The changes to my sex life bother me (n = 106)	Strongly Disagree	2 (1.9)	2 (100.0)	0 (0.0)
	Disagree	2 (1.9)	2 (100.0)	0 (0.0)
	Neither Agree Nor Disagree	6 (3.8)	4 (66.7)	2 (33.3)
	Agree	47 (44.3)	29 (61.7)	18 (38.3)
	Strongly Agree	49 (46.2)	35 (71.4)	14 (28.6)

[a] Total sample size was 125 after 11 participants were removed (7 who could not remember whether they had talked or not talked, and 4 who were excluded due to contradictory data elsewhere in the survey to their response to the question about whether they had talked or not talked).

[b] 31/125 participants were unsure of their cancer stage.

aforementioned variable, they had also explicitly contradicted their response in other parts of the survey. Therefore, 125 participants have been included in the analysis that was related to discussions about sexual health/wellbeing in this paper.

Results show that for almost all survey variables, the majority of participants did not talk to the hospital cancer team about their sexual health. The only exceptions to this were for those diagnosed with a genitourinary cancer, or for those diagnosed with cancer less than 6 months ago.

3.2. The impact of cancer and its treatment on the sexual health of people with cancer in the UK

Table 1 (where n = 125) shows that the majority of participants (68.8%) had had sexual activity in the past year, either alone or with a partner. Furthermore, the majority also reported a worsening of their sex lives (84.8%) with 90.5% of these particular participants being bothered by this worsening.

Additional data related to sexual activity that was not included in Table 1 is provided next and is for the complete sample of n = 136 (rather than the restricted sample of n = 125). Types of sexual activity reported by people with cancer (n = 93) included self-pleasuring 64.5%; with a partner 89.2%; and in a group 2.1%. The main reasons provided for sexual inactivity (in the past year or past month) related to people with cancer themselves n = 65 (as opposed to being due to their partners). Reasons included being too tired (40%), not being interested (52.3%) and having a physical problem that makes sex difficult or uncomfortable (55.4%).

Quantitative results from the researcher generated questions in which participants (n = 136) were asked to specify their level of agreement with four additional statements about sexual health following cancer/cancer treatment included the following findings. The majority of participants agreed/strongly agreed that sexual confidence worsens following cancer/cancer treatment (83.1%) and that sexual changes lead to problems in relationships (55.1%). Furthermore, the majority also agreed/strongly agreed that being with a new partner would be difficult (80.8%) and that those starting new relationships would need extra support from the hospital cancer team (76.4%).

Qualitative results included eighty-nine people with cancer having responded to the open-ended item from the long version of the SFQ, which offered the opportunity to provide details about how sex had changed since their illness/treatment - some also commented in other parts of the survey about how their sexual lives had changed. Reflexive

Table 2
Reflexive thematic analysis of comments regarding changes to sex life since cancer/cancer treatment from a UK cross-sectional survey on care for sexual health in people with cancer (n = 89).

Theme	Description of theme/subthemes	Exemplar comments
Theme 1 **Biological Changes -** All these bodily changes make sex difficult, uncomfortable or even impossible *The largest number of participant comments related to this theme with females dominating.*	**Sex is difficult** • Bodily changes made the sex lives of some participants more difficult. The loss of various body parts and the creation of new body parts was said to contribute.	“I had 1.2 [half] my tongue cut out. What I would do for a proper snog”, *a female with a head and neck cancer and a gynaecological cancer*
	Sex is uncomfortable	“Feels like a knife cutting me when we have sex.” *A female with a blood cancer*
	Sex is impossible • Penetrative intercourse had become impossible for some participants due to bodily changes.	“vagina became impenetrable either due to chemo or surgery […]”, *a female with a gastrointestinal cancer*
	Increased levels of fatigue	“Plus tiredness means I’m just not interested.”, *a person (unwilling to disclose sex/gender) with a stage 3 blood cancer*
Theme 2 **Biological Changes -** My sexual self just doesn’t work any more *Many participants commented on the impact of cancer treatment on their sexual function.*	**Lack of Interest** • The largest number of participants in this theme described how their interest in sexual activity had either decreased or been lost completely.	“The urge to want to have sex was almost daily before the treatment. During and after treatment, I rarely think about sex”, *a male with a stage 1 blood cancer*
	Arousal Difficulties • More male than female participants commented on how arousal had been impacted following treatment	“I find it very difficult to get or sustain an erection”, *a male with a blood cancer*
	Hormonal Changes • Both males and females commented on hormonal changes which impacted their sexual lives. • Surgically induced menopause was singled out by women as a particularly difficult experience (Few commented on orgasm and sexual satisfaction)	“I was plunged into menopause, with all the sexual issues that come with that - thinning of the skin in the vagina meaning that penetrative intercourse is painful”, a *female with a stage 3 gynaecological cancer*
Theme 3 **Psychological changes –** I don’t feel good about myself	**Self-esteem, body image and sexual confidence** • Reductions were reported	“I’ve been suffering from ED [erectile dysfunction], low self esteem and depression for many years since the operation. […] *a male with a genitorurinary cancer*
	Grief • Some participants also commented on the grief that they had experienced following the changes to their sex lives.	“My wife and I were still quite sexually active up until I was diagnosed with myeloma. Our sex life dwindled over time the more treatment(s) I had, the less frequent the love making, until such time as I became totally impotent. Myeloma has cost me my job, my ability to earn an income, even part time, my full pension. We had to give up our caravan as we could no longer perform the tasks to pitch it up, but the one thing I resent the most of all, is losing the ability to perform sexually”, *a man with a blood cancer*
Theme 4 **Psychological changes –** Sex is frightening now	• A small number of participants commented on how sex had become something that was frightening, either just the thought of it or for some particular reason such as it might hurt or because it might make their condition (the cancer) worse.	“I am scared to have sex” *a female with a stage 2 blood cancer*
Theme 5 **Changes to sex life –** I/we gave up	• Participants commented on how their sex lives had either reduced or stopped completely since cancer treatment.	“My Cancer damages my bones and the last occasion I had sexual relationship with my husband my ribs got broke. […] Our relationship is now no existent we do not even hold hands anymore. It is very distressing”, a *female with a blood cancer*
Theme 6 **Changes to sex life –** It’s not what it was	• Participants also commented on how the quality of their sex lives had changed with some mentioning how penetrative sex was no longer possible and others mentioning how sexual satisfaction had been reduced.	“I find it very difficult to get or sustain an erection. Even when I do get an erection I don’t have the same feeling as before. Sometimes I feel as if I do have an erection but I don’t. I have no idea when I’m going to ejaculate and sometimes this happens without an erection. My semen is very thin and watery”, *a male with a blood cancer*

thematic analysis led to the development of six themes, which are presented in Table 2.

Participants who reported biological changes following cancer treatment, which made sex difficult, uncomfortable or even impossible plus those with increased levels of fatigue (theme 1), were overwhelmingly female. Moreover, the changes they reported were not confined to the vagina or breasts but were related to other parts of the body as well (e.g. shoulders, legs and sense of smell). Whereas those who reported that their sexual self did not work anymore (theme 2), were majority female with respect to difficulties with interest in sex but majority male for those reporting difficulties with arousal. However, one participant did comment that her interest in sex was only temporarily lost and a resumption of intimacy made her feel better or "normal".

The two psychological themes also found that more women than men reported on how cancer treatment had impacted their sex lives. This was particularly the case for the theme related to sex becoming frightening after cancer treatment (theme 4). Comments were almost entirely negative in relation to theme 3, in which participants reported on how they no longer felt good about themselves. However, one participant did report that cancer had a positive effect and that she developed a new zest for life and a new deeper love for her partner".

With regards to changes in the quality and quantity of sex following cancer treatment, both males and females commented. Although, a reduction in satisfaction was particularly noted by females. However, a small number of participants did report that they had found different ways of having a sex life but this development occurred via self-help rather than via support from the hospital cancer team.

3.3. Discussions about sexual health in UK hospital cancer care: nature and proportions

For those who talked about sexual health/wellbeing with their hospital cancer team, Table 3 shows details about these discussions in terms of whether a discussion took place plus the details regarding what was discussed, when and with whom. Results showed that the majority of people with cancer (61% (n = 83)) agreed that they had never discussed their sexual health with the hospital cancer team. Only 30.9% recalled a discussion about the topic, 5.1% were unable to remember whether they

Table 3

The nature and proportions of discussions about sexual health with the hospital cancer team in the UK, as reported by PWC[a] in a cross-sectional survey on care for sexual health.

Variables		n	%
Did the HCT[c] ever talk about sexual health/wellbeing?			
n = 136	No	83	61.0
	Yes	42	30.9
	I cannot remember	7	5.1
	Excluded	4	2.9
For those who ever talked about sexual health with the HCT			
Who initiated the discussion?	PWC	18	42.9
n = 42	PoPWC[b]	3	7.1
	The HCT	21	50.0
	I Cannot remember	0	0.0
When did you talk about sexual health?	Before treatment	25	59.5
(*Per case agreement with each option)*	During treatment	14	33.3
n = 42	Following treatment	11	26.2
	Other	2	4.8
	I Cannot remember	0	0.0
Who did you to talk to**?**	Surgeon	10	23.8
(*Per case agreement with each option)*	Oncologist	16	38.1
n = 42	Clinical Nurse Specialist	22	52.4
	Chemotherapy Nurse	6	14.3
	Radiographer	1	2.4
	Cancer Support Worker	1	2.4
	Other	6	14.3
What did you talk about (in relation to sexual concerns)?			
(*Per case agreement with each option)*			
n = 42	Potential sexual side effects of cancer treatment	22	52.4
	Fertility	13	31.0
	Contraception	12	28.6
	When can resume sexual activity	16	38.1
	Risks of sexual activity during cancer treatment	17	40.5
	Sexual function (interest/arousal/orgasm/sexual satisfaction)	13	30.9
	Menopause	6	14.3
	Psychological: body image/confidence/emotional difficulties	5	11.9
	Social: relationship concerns	0	0.0
	Sexual renegotiation	1	2.4
	Prevention of sexual problems	0	0.0
	Information sources on sexual wellbeing	1	2.4
	Managing or treating sexual problems	6	14.3
Overall satisfaction with care for sexual health			
Overall satisfaction with care received for sexual health from the hospital cancer team?			
n = 136	Very dissatisfied	24	17.6
	Dissatisfied	41	30.1
	Neither satisfied nor dissatisfied	55	40.4
	Satisfied	14	10.3
	Very satisfied	2	1.5

[a] PWC: people with cancer.

[b] PoPWC: partners of people with cancer.

[c] HCT: hospital cancer team.

Table 4

Analysis of pre-treatment discussions about the sexual side effects of cancer treatment in the UK, as reported by PWC[a] in a cross-sectional survey on care for sexual health (n = 125).

	Number of participants agreeing with each item					
	Sexual side effects of cancer treatment N (% of total[b])	Fertility N (% of total[b])	Menopause N (% of total[b])	Sexual Function: Interest N (% of total[b])	Sexual Function: Arousal N (% of total[b])	Sexual Function: Orgasm N (% of total[b])
Was this potential sexual health side effect ever discussed?	22 (17.6)	13 (10.4)	6 (4.8)	4 (3.2)	5 (4)	3 (2.4)
Was this potential sexual health side effect discussed pre-treatment?	15 (12)	10 (8)	4 (3.2)	3 (2.4)	3 (2.4)	3 (2.4)
Was the discussion initiated by PWC[a] or the PoPWC[c]?	7 (5.6)	3 (2.4)	0 (0.0)	1 (0.8)	2 (1.6)	3 (2.4)
Pre-treatment discussions unlikely to have been related to informed consent	1 (0.8)	0 (0.0)	2 (1.6)	0 (0.0)	0 (0.0)	0 (0.0)
Participants who potentially received informed consent for a sexual health side effect in a pre-treatment discussion that was initiated by a member of the HCT[d]	7 (5.6)	7 (5.6)	2 (1.6)	2 (1.6)	1 (0.8)	0 (0.0)

[a] PWC: people with cancer.

[b] % of total relates to the total number of participants who answered yes or no to the question about whether participants ever talked to the HCT about sexual health, where n = 125.

[c] PoPWC: partners of people with cancer.

[d] HCT: hospital cancer team.

had a discussion (2.9% were excluded) when n = 136.

The majority of those who had a discussion reported having discussed sexual health pre-treatment but few reported this happened following treatment. The clinical nurse specialist (CNS) was the most frequently mentioned member of the hospital cancer team with whom participants spoke about their sexual health. The most frequently discussed topics were the sexual side effects of cancer treatment (SSECT) and sexual safety (when to resume and what are the risks of sexual activity). Overall satisfaction with the care received for sexual health from the UK hospital cancer team was low with only 11.8% of the total sample (n = 136) being satisfied/very satisfied. However, 40.4% of the sample neither agreed nor disagreed with this statement, and 47.7% were dissatisfied/very dissatisfied.

3.3.1. *The estimated proportion of people with cancer providing informed consent for the sexual side effects of cancer treatment*

Results were also analysed to estimate the likely proportion of those providing informed consent for the SSECT. Findings were based on combining individual participants' reports about what was discussed, with whom, and when. Table 4 shows the proportions of participants who reported having had a pre-treatment discussion about the SSECT. Whilst 12% of the sample reported having talked to any member of the hospital cancer team about the SSECT pre-treatment, 5.6% of these did so because they or their partner initiated the discussion themselves. A further 5.6% of the total sample reported having had a discussion that was initiated by the hospital cancer team at the pre-treatment timepoint - these discussions occurred with 4 doctors (3.2%) and 3 (2.4%) nurses. It is not clear from these data whether these nurses would or would not have been receiving informed consent for cancer treatment.

Similarly low numbers also reported having discussed the other sexual health topics noted in Table 4 including fertility, menopause or sexual function issues (i.e. interest, arousal and orgasm). These are shown as separate items because some participants may have reported that they discussed these issues plus or minus the catch all category of SSECT at the pre-treatment timepoint.

Sexual safety relates to the timing of a resumption of sexual activity and also to the associated risks of sexual activity during cancer treatment. These topics have not been included in Table 4 because, whilst being important for maintaining safety for patients and their partners, it is not a side effect as such. However, the majority of those who reported that they discussed sexual safety were included in Table 4 because they had also discussed the SSECT, fertility, menopause or sexual function.

In summary, the analysis shows that whilst 12% of the sample discussed the SSECT pre-treatment, only 5.6% had a pre-treatment discussion that was initiated by a member of the hospital cancer team.

4. Discussion

4.1. *Key results*

This survey has shown that the sex lives of the majority of participants worsened following cancer treatment with a wide range of biopsychosocial changes having been reported, which were found to bother the majority of participants whose sex lives had worsened. This survey also showed that the majority of the sample, regardless of their personal characteristics, did not discuss their sexual health with the hospital cancer team. Results additionally revealed that very few participants reported having had a pre-treatment discussion about sexual health in a manner that was likely to have been consistent with the provision of informed consent for the SSECT. Furthermore, even fewer reported having discussed sexual health post-treatment.

4.2. *Interpretation of results*

4.2.1. *The impact of cancer and its treatment on the sexual health of people with cancer in the UK*

Results of this study found difficulties with sexual health continue to be both broad ranging and common. These findings were consistent with recent studies in prostate and breast cancer that also revealed high rates of sexual health difficulties (Downing et al., 2019; Jing et al., 2019). Results from this survey's open-ended question about changes to respondent's sex lives showed how females reported on a broader range of biological and psychological changes to their sex lives than males. Fewer participants commented on social (relationship) changes, and thus no themes were created in relation to this aspect of life. However, a small number of participants did comment on how supportive and loving partners had helped them cope with the changes. Whereas, actual renegotiation of the sexual relationship was rarely reported, and when it was, it was via self-care rather than the hospital cancer team.

Evidence exists to show that the frequency of sexual activity decreases with increasing age in the general population, and also that the prevalence of sexual health problems generally increases with age (Lee et al., 2016). It should be pointed out that the age of participants in this survey reflects the fact that cancer tends to be a disease of the elderly with 78.4% of participants being over 50 years old. UK cancer statistics for England show that 79% of women and 89% of men are 55 years of age or older when diagnosed with cancer (Baker and Mansfield 2023 p. 10). Previously established impacts of age on sexual activity, are less salient for the results of this survey because participants were being asked about a comparison of their sex lives pre and post cancer treatment. Notwithstanding the reported decrease in interest in sex following cancer treatment found in this survey, Derogatis and Kourlesis (1981) pointed out that men and women, despite some reduction in interest, can remain sexually active into their sixth and seventh decades. They argue that the myth that elderly individuals are not interested in sex may have a disproportionate influence on people with cancer because of the higher incidence of cancer in the elderly.

4.2.2. *Discussions about sexual health: overall proportions*

Whilst the overall sample size was relatively small, the required minimum number of participants was reached within the protocol-specified recruitment period and thus recruitment was stopped after 5 weeks. The implications of this relatively small overall sample size can be observed in the very small numbers of participants with various socio-demographic and cancer characteristics reported in Table 1. However, Table 1 also shows that for the majority of variables, a majority of participants consistently reported that no one ever talked to them about their sexual health/wellbeing during their cancer journey. The only exceptions to this were for two variables in the cancer characteristics section. These exceptions included those with a genitourinary cancer and those who had been diagnosed less than 6 months ago, where approximately 45% had not talked.

The high proportion of those who reported a worsening of their sex lives in this survey contrasted starkly with the low proportion of those who reported that they had a discussion about sexual health with the hospital cancer team. This discrepancy, supports the need for further explanation of the lack of care for sexual health. In particular due to the fact that, regardless of participants' socio-demographics, cancer characteristics, or the level of impact on their sexual activity, the majority reported that they had not talked about sexual health/wellbeing with the hospital cancer team. Out of 125 participants, 66% per cent of participants self-reported never having talked about sexual health during their cancer care. Very similar results were also found in a recent survey of women with breast cancer in France (Aupomerol et al., 2022). Both these findings are also consistent with a recent systematic review which showed that amongst the 16 included oncology studies, only 24.2% (95% confidence interval, 22.1–26.3) of HCPs reported usually/regularly/always asking about sexuality (McGrath et al., 2021).

Reports of sexual health communication in oncology have been found to vary between studies, tumour sites, and countries. For example, 79% of people with prostate cancer have reported discussing sexual health, whereas only 17.3% of those with a gynaecological cancer reported the same (Zhang et al., 2020). Whereas some geographically disparate studies from the US, Iran and China have produced strikingly similar reports about the proportion of those who discussed sexual health in breast and gynaecological cancer patients of approximately 6–8% (Chen et al., 2021; Masjoudi et al., 2019; Zimmaro et al., 2020). Although Zimmaro et al. (2020) only reported on the proportions of those who discussed sexual health during the previous month (in the US), as opposed to ever having discussed sexual health. However, in the current survey, all tumour sites reported that a majority of participants had not discussed sexual health (except for in genitourinary cancers, and for those diagnosed less than 6 months previously).

The salience of sexual health impacts and communication about these impacts have been anticipated to vary with age. Fitch et al. (2013) found that HCPs considered that a patient's age may influence the patient's comfort in talking about sexual health. However, this survey's sample (n = 125) was majority over 50 years old (78.4%), and 84.8% (n = 106/125) reported that their sex lives had worsened and 90.5 % of these were bothered by this deterioration. This may be interpreted as sexual health mattering to those over 50 years old.

Although few participants were satisfied with the care they received for their sexual health, 40.4% of the total sample (n = 136) neither agreed nor disagreed with being satisfied or dissatisfied. It is unclear why such a large number responded in this manner. However, this may relate to perceptions of priorities in cancer care with sexual health not being seen as a priority (Zangeneh et al., 2023; McCaughan et al., 2020).

4.2.3. *Pre-treatment discussions about sexual health: nature and proportions*

Results of those participants who did discuss their sexual health with the hospital cancer team were analysed more closely (in terms of what was discussed, when and with whom). The analysis showed that very few participants received a pre-treatment discussion about the SSECT that was initiated by a member of the hospital cancer team (Tables 3 and 4). This implies that the majority of participants, regardless of whether or not they had a discussion about sexual health with the hospital cancer team, were unlikely to have provided informed consent for the SSECT. The proportion of discussions about sexual health that were initiated by people with cancer or their partners have been reported because sexual health has been identified as a difficult topic to raise (Perz et al., 2013). As such it is possible that the topic was raised because it had been omitted by the hospital cancer team, which suggests that the topic may not be part of the routine consent process. Patients/partners needing to raise the topic themselves does not give confidence that the topic was a routine part of the informed consent process. It appears that the hospital cancer team may not have sufficiently satisfied themselves that their patients were adequately informed about the SSECT. This consideration would likely reduce the aforementioned estimate of informed consent for the SSECT of 12% (figure for pre-treatment discussion about sexual health when the topic was raised by either the hospital cancer team or patients/partners) to between 5.6% if both doctors and nurses received consent or 3.2% if only doctors received consent. Guidance issued by the UK Chemotherapy Board (2018) on consent for systemic anti-cancer therapy (SACT) stated that appropriately trained and experienced, non-medical members of the hospital cancer team can receive consent for cancer treatment.

Others have found similar results in surveys of oncology healthcare professionals, with only 5% of Dutch medical oncologists (Krouwel et al., 2020) and 23.2% of Dutch surgical oncologists (Krouwel et al., 2015a) reporting that they often/always inform patients about sexual health side effects during an informed consent discussion. A study which retrospectively reviewed the medical records of 52 people with rectal cancer found no documented evidence of a presurgical discussion of the risks of sexual dysfunction in 71% of participants (Chorost et al., 2000). However, contrasting results have been found in other qualitative studies. For example, a study that recorded clinic conversations (n = 81) found that sexual dysfunction was discussed with the majority of people with rectal cancer prior to pre-operative radiotherapy (Kunneman et al., 2015). Other qualitative, interview studies found HCPs reported that sexual health communication occurred mostly in the context of informed consent prior to treatment (Maree and Fitch, 2019; Fitch et al., 2013).

Krouwel et al. (2015b) also conducted a survey amongst Dutch nurses which found that almost all agreed that discussing sexual function was their responsibility but that approximately half of them did not routinely discuss sexual function. If the hospital cancer team regard sexual health as a nursing responsibility this could contribute to neglect of the issue during the informed consent process in oncology settings where medical staff may be the main members of staff receiving informed consent.

4.2.4. *Informed consent and the SSECT*

The majority of this sample self-reported that they never discussed sexual health with the hospital cancer team at any point during their cancer journey, which implies that the majority were not provided with a sufficient understanding of the SSECT to provide informed consent to cancer treatment. However, even amongst participants who did discuss sexual health with the hospital cancer team, results showed that few implied that they provided informed consent for the SSECT, which was unexpected. It is not appropriate that the SSECT come as a surprise, as one participant from this survey noted, "I was completely unaware that it would become a problem after completing treatment." (a female with stage 3 breast cancer whose sex life was a lot worse than before cancer treatment).

The previously mentioned models/frameworks for discussing sexual health in cancer care tend to recommend raising the topic both early and repeatedly during cancer care rather than advising on a very specific timepoint to begin discussing sexual health. Some cancer guidelines also recommend that the SSECT are raised at diagnosis and/or periodically throughout follow-up, in prostate cancer specifically (National Institute for Health and Care Excellence (NICE) 2019) and in cancer more broadly (Carter et al., 2018). Whilst UK and European breast cancer guidelines do not appear to mention that the SSECT should be discussed (NICE, 2018; Cardoso et al., 2019). What is notable about cancer specific guidelines and the aforementioned models/frameworks for discussing sexual health is that they either do not specifically recommend bringing up the SSECT during the informed consent discussion, or do not clarify how this can be achieved at this particular timepoint. This inattention may contribute to the continuing low levels of sexual health discussions in cancer care. Particularly when coupled with the long list of non-sex-related risks and benefits that need to be discussed prior to any type of cancer treatment, along with the fact that sexual health is a sensitive and difficult topic to discuss. This multitude of factors make it unsurprising that, at this time-pressured point in care, the inclusion of sexual health during informed consent appears to be a rare event.

Enabling adequate consent, for systemic anticancer therapy (SACT) in particular, was one of the aims of the UK Chemotherapy Board's guidance (2018), which was endorsed by a variety of UK medical, nursing and pharmacy bodies and was also supported by the charity, Cancer Research UK. These guidelines provided renewed procedural guidance for consent that was based on existing guidance documents from the UK Department of Health, the UK General Medical Council, the British Committee for Standards in Haematology and 2015 UK case law. It included advice on informing about side effects. The UK NHS website similarly advises the public that valid consent requires information about both the risks and benefits of treatment (NHS, 2022). Guidance on informed consent in general states that consent discussions should contain information on all the risks and benefits of any proposed treatment making it imperative that the SSECT are discussed with all people with cancer prior to cancer treatment. Such action may also serve to motivate local hospital cancer teams to organise the subsequent what/when/and by whom of care for the SSECT, which may also improve the proportion of those receiving a post-treatment discussion along with subsequent access to information, advice and treatment. The importance of information can also be seen in a statement by WHO (2024b), in which the ability to achieve sexual health is considered to depend upon access to quality information about sex and sexuality.

4.3. Limitations

Whilst the planned sample size was met within the planned recruitment period, the achieved sample size of 136 is considered relatively small for a quantitative research study.

In order to reduce the potential for sampling bias, 20 charities representing a broad range of cancer types helped with recruitment during two rounds of advertising. To limit volunteer bias, study advertisements mentioned sexual health and wellbeing to encourage those both with and without problems to participate. Advertisements also emphasised that sexual health can be impacted in physical, psychological and interpersonal ways to encourage broader interest.

The variations in numbers of cancer types likely reflected the varied approaches to advertising used by the different cancer charities. In particular, the major breast and prostate cancer charities were unable to advertise the survey as widely as had been hoped. Furthermore, the use of cancer charities' social media channels limited participation to those who utilise both. Creation of a pencil and paper version of the survey was considered but study resources were insufficient to enable this.

Further limitations of retrospective, self-reporting by people with cancer on the occurrence of sexual health communication were shown in a study by Reese et al. (2020). The authors found the frequency of self-reported discussions to be inconsistent with actual, recorded clinic dialogue, and suggested that multiple items should be used to assess the frequency of discussions and that this may potentially improve the accuracy of patients' recall. This recommendation was adhered to, as an attempt was made to minimise any recall bias related to the initial variable in the care for sexual health section of the survey 'did the hospital cancer team ever talk about sexual health/wellbeing at any time during cancer care?'. This was done by providing 19 examples of things that may have been discussed, which may have acted as a memory aid and improved recall (see supplementary data file 1 page 19).

Self-reporting did lead to some discrepancies between participants' responses to the question about whether people with cancer had ever talked to the hospital cancer team about sexual health, and their responses to other variables in the survey. Where explicit contradiction occurred, participants were removed from the analysis related to discussing sexual health.

The analysis of data estimating the proportion of participants providing informed consent for the SSECT also had limitations. It was not possible to confirm whether or not any of the particular discussions that did occur, actually took place during the informed consent process for cancer treatment. This was due to the fact that this question was not explicitly asked.

Finally, this convenience sample afforded little diversity in terms of ethnicity and gender. Additionally, no intersex participants took part. However, the percentage of the sample identifying as heterosexual (88.6% (n = 117/132)) was lower than that in the general UK population (93.6%) (ONS, 2022).

4.4. Generalisability

Whilst this sample was a convenience sample and as such is not generalisable, it did provide some variety socio-demographically and in terms of cancer characteristics. At the very least, results indicate the need for clinicians to review their practice to ascertain whether or not patients are provided with sufficient information to enable informed consent.

4.5. Conclusion

The recalcitrance of low rates of sexual health communication over recent decades is dispiriting and indicates that more radical strategies to those currently in operation are required if cancer patients are to receive excellent, or even adequate, sexual health care.

Analysis of the nature of discussions about sexual health and the proportions of those reported revealed that very few participants were likely to have provided informed consent for the SSECT. Current cancer guidelines and models/frameworks for enabling sexual health care in oncology do not always emphasise the need to include SSECT during informed consent to cancer treatment nor do they advise on how to do this at such a challenging timepoint. The UK Chemotherapy Board (2018) argue that 'unique uncertainties' are present during the SACT consent process with respect to the balancing of risks and benefits for each individual, and as such obtaining consent requires considerable expertise. Considering this guidance alongside the known difficulties of discussing sexual health then HCPs may require specific advice on how to bring up sexual health during the informed consent process itself.

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Data statement

Raw data will not be shared in an online repository, as it was explicitly stated in participant information sheet that this would not happen.

Registration

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CRediT authorship contribution statement

Suzanne Sheppard: Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **David Culliford:** Formal analysis, Methodology, Writing – review & editing. **Tracy Glen:** Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing. **Sally Lee:** Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing, Formal analysis. **Zoë A. Sheppard:** Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing. **Sam Porter:** Conceptualization, Funding acquisition, Methodology, Supervision, Writing – review & editing, Formal analysis.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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