

Talking about sex with health professionals: the experience of people with cancer and their partners

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GILBERT E., PERZ J. & USSHER J.M. (2016) *European Journal of Cancer Care* **25**, 280–293
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Changes to sexuality can be one of the most difficult aspects of life following cancer. This study examines the experience of discussing sexuality post cancer with health care professionals (HCPs), from the perspective of women and men with cancer (PWC), and their partners (PPWC), across a range of cancer types. A total of 657 PWC (535 women, 122 men) and 148 PPWC (87 women, 61 men) completed a survey containing closed and open-ended items, analysed by analysis of variance and thematic analysis. Discussions about sexuality with a HCP were more likely to be reported by men (68%) compared to women PWC (43%), and by women (47%) compared to men PPWC (28%), as well as by those with a sexual or reproductive cancer. Men PWC and women PPWC were most likely to want to discuss sexuality with a HCP, with men PWC and PPWC reporting highest levels of satisfaction with such discussions. Open-ended responses revealed dissatisfaction with the unwillingness of HCPs to discuss sexuality, unhappiness with the nature of such discussion, and positive accounts of discussions about sexuality with HCPs. These findings lend support to the notion that people with cancer and their partners may have unmet sexual information and support needs.

Keywords: communication with health professionals, mixed method survey, patient and partner perspectives, sexual and non-sexual cancers, sexual well-being after cancer.

INTRODUCTION

Researchers have consistently demonstrated that changes to sexuality can be experienced as one of the most difficult aspects of life following cancer (Anderson & Golden-Kreutz 2000). Such changes are multi-faceted; linked with a range of negative physical and emotional outcomes for both people with cancer and their partners (Katz 2005; Gilbert *et al.* 2010; Perz *et al.* 2014), as well as changes to roles and intimate relationships (Hawkins *et al.* 2009; Lindau *et al.* 2011). There is evidence that people with cancer and partners report the need for infor-

mation about sexuality after cancer from health professionals (Hautamäki-Lamminen *et al.* 2013); however, such information provision is often inadequate or absent (Fallowfield & Jenkins 1999; Flynn *et al.* 2012). Particular areas of unmet need include open communication about post-cancer physical and sexual changes (Landmark *et al.* 2008), effects of treatments on sexuality and body image (Ussher *et al.* 2013a), changes to intimate relationships (Hordern & Street 2007a) and psychological support (Landmark *et al.* 2008). Absence of communication and information can leave people with cancer and partners feeling that they are sexually 'abnormal', unprepared for the sexual side effects of cancer and treatments, lacking in knowledge about the cause and duration of their sexual problems (Stead *et al.* 2003), and depressed, or disappointed with health professionals (Vogel *et al.* 2009). In contrast, being provided with information and being included in an open discussion about sexuality can

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Accepted 12 June 2014
 DOI: 10.1111/ecc.12216

European Journal of Cancer Care, 2016, **25**, 280–293

alleviate the anxiety around post-cancer sexual changes, assist people with cancer to discuss sexuality with their partner (Stead *et al.* 2003; Perz *et al.* 2013), minimise the negative impact on intimate relationships (Rasmusson & Thome 2008), and enhance quality of life (Vogel *et al.* 2009).

Although health professionals increasingly position sexuality as an important topic of discussion in the context of cancer (Stead *et al.* 2003; Perz *et al.* 2013), this does not always translate into practice (Lindau *et al.* 2011). Researchers have identified a number of barriers that have been reported to prevent health professionals from raising sexuality and meeting the sexual information needs of people with cancer and partners, including avoiding the issue of sexuality because it is an 'uncomfortable' or embarrassing topic (Stead *et al.* 2003), positioning sexuality as 'too risky' to raise amongst single, older, non-western people, or people who are considered 'too sick' (Greene & Adelman 2003; Hordern & Street 2007b; White *et al.* 2013), absence of a private space for discussion (Ussher *et al.* 2013c) and feeling ill-equipped to provide answers about sexual concerns (Lindau *et al.* 2011). It has also been argued that health professionals work dominantly within a 'clinical culture' (Hordern & Street 2007a) that tends to be more 'cure-oriented' than 'care-oriented' (Ong *et al.* 2000), and subscribes to an essentialist biomedical view of sexuality which may limit discussion to issues such as treatment-induced infertility, erectile dysfunction, loss of libido, or contraception (Hordern & Street 2007a, see also White *et al.* 2013). However, there is evidence that people with cancer also want health professionals to discuss the appropriateness of sexual activity (Rasmusson *et al.* 2013), sexual positioning or the use of sexual enhancement products (Herbenick *et al.* 2008), adjustment to sexual changes (Ussher *et al.* 2013a), and the expansion of sexual repertoires outside a heteronormative frame (Archibald *et al.* 2006). Further research is needed to examine patient and partner interactions with health professionals in the context of sexuality and cancer: the aim of the present study.

To date, research that has addressed whether the sexual needs and concerns of people with cancer are met by health professionals is limited in a number of ways. Such research has focused almost exclusively on either men or women, and on cancers that directly affect reproductive or sexual sites of the body (for an exception see Hordern & Street 2007a), including breast (Ussher *et al.* 2013a), gynaecological (Stead *et al.* 2003), prostate and testicular cancers (Danile & Haddow 2011; Jankowska 2012). However, there is increasing evidence that both men and women across a range of cancer types report changes to

their sexuality post cancer (Perz *et al.* 2014), including lung (Lindau *et al.* 2011), lymphatic (Jonker-Pool *et al.* 2004; Jarden *et al.* 2012), colon (van der Horst-Schrivers *et al.* 2009), non-Hodgkin lymphoma (Beckjord *et al.* 2011), head and neck (Low *et al.* 2009), and colorectal cancer (Beck 2009). Despite this, health professionals have been reported to be less likely to discuss sexual changes with individuals or couples experiencing a non-sexual cancer (Ussher *et al.* 2013c).

The sexual needs and concerns of intimate partners of a person with cancer are also notably absent from most existing research examining health professional communication about sexuality post cancer. This may stem from an individualist view of sexuality, where sexual problems are seen as residing within the body (Teifer 1996). However, it is well documented that intimate partners desire communication and information about post-cancer sexual changes to their own sexual selves and their relationship (Gilbert *et al.* 2009), with some evidence that partners have a greater need for information than people with cancer (Lavery & Clarke 1999; Rees & Bath 2000). In addition, people with cancer have reported that it is important for their intimate partner to be included in discussions about sexuality with health professionals (Ellingson & Buzzanell 1999; Flynn *et al.* 2012), with open communication between people with cancer and their partner key to managing changes to sexuality (Lavery & Clarke 1999; Badr & Carmack Taylor 2009). This open communication has been found to be easier if health professionals include both the person with cancer and the partner in discussions about sexuality (Rasmusson & Thome 2008).

Finally, the vast majority of research examining interactions with health professionals about post-cancer sexuality has relied solely on standardised quantitative instruments to assess patient satisfaction with, or the effectiveness of, health professional communication and information (Ong *et al.* 2000). Such research has negated the subjective meanings and constructions people with cancer and intimate partners attach to interactions with health professionals (see Ellingson & Buzzanell 1999; Powel & Clarke 2005). Whilst an increasing number of researchers adopt qualitative methods to examine these subjective experiences (e.g. Hordern & Street 2007a; O'Brien *et al.* 2011), such research is in the minority, due perhaps to the critique of small sample size and lack of representativeness. In order to overcome this, mixed-method research, involving open and close-ended responses to surveys, as well as interviews, allows a larger number of participants to be investigated, at the same time as capturing subjective meanings (Creswell 2009). The present mixed-methods study will examine experiences of discussing sexuality

with health professionals, from the perspective of men and women across a range of cancer types, and the intimate partners of people with cancer. Using a combination of written survey items and in-depth interviews, we address the following research questions: 'Have people with cancer and partners engaged in a discussion with a health professional about sexuality?'; and 'How do people with cancer and partners construct and experience interactions about sexuality with health professionals?'

METHOD

Participants

A total of 805 participants took part in the study: 657 people with cancer (PWC; 535 women, 122 men) and 148 intimate partners of a person with cancer (PPWC; 87 women, 61 men), as part of a larger mixed methods project examining the construction and experience of changes to sexuality after cancer (Perz *et al.* 2013; Ussher *et al.* 2013c). After receiving ethics approval from the University Human Research Ethics Committee, and from three Area Health Services, participants were recruited nationally through cancer support groups, media stories in local press, advertisements in cancer specific newsletters, hospital clinics, and local cancer organisation websites and telephone helplines. The inclusion criteria were self-reported past or current diagnosis with cancer, or being the partner of a person with cancer, and being over 18 years of age. A person with cancer and an intimate partner, nominated by a cancer consumer organisation, acted as consultants on the project, commenting on the design, method and interpretation of results.

Procedure

Survey

Participants completed an online or postal questionnaire examining their experiences of sexuality and intimacy post cancer, using a combination of closed and open-ended items. The following closed and open-ended questions about experiences of discussing sexuality with health professionals form the basis of the present analysis.

Discussion of sexual concerns. A single item measure developed as part of the study to assess whether participants had engaged in a discussion about sexual concerns with a health professional since the onset of cancer, using a yes/no response.

Wanting a discussion of sexuality with a health care professional. Participants who indicated that they had not engaged in a discussion about sexuality with a health

professional were asked if they would have liked a health care professional to raise the issue, using a yes/no response.

Initiating a discussion of sexuality. Participants who indicated that they had engaged in a discussion about sexuality with a health professional were asked to indicate who raised the issue: health care professional; your partner; yourself; both you and your partner.

Satisfaction with discussion of sexuality. Participants who indicated that they had engaged in a discussion about sexuality with a health professional, were asked how satisfied they were with the discussion on a five-point scale: very satisfied; satisfied; neither satisfied nor dissatisfied; not satisfied; not at all satisfied.

Open-ended responses about discussion of sexuality with health care professionals. Participants provided qualitative responses to the following open-ended question: 'Do you have any other comments you would like to make about your experience in discussing sexuality issues with a health care professional?'

In-depth interviews

At the completion of the survey, participants indicated whether they would like to be considered to take part in a one-to-one interview, to discuss changes to sexuality in more depth, as well as experiences of communication and information provision about sexuality from health professionals. Of the 805 survey respondents, 274 responded positively to the invitation. We purposively selected 79 participants for interview, 44 people with cancer (23 women, 21 men) and 35 partners in an intimate relationship with a person with cancer (18 women, 17 men), representing a cross section of cancer types and stages, gender, and sexual orientation, reflecting the larger study population. The participants were not matched pairs; individuals could participate in an interview regardless of whether their partner was taking part. Individual semi-structured interviews were conducted on a face-to-face (7) or telephone basis (72) by two interviewers, a man and a woman. Telephone interviews have previously been recommended for interviews regarding sensitive, potentially embarrassing topics (Sturges & Hanrahan 2004), such as cancer and sexuality, and pilot interviews indicated that they were an effective modality to utilise in this study. Prior to the interview, participants were sent an information sheet and consent form to read and sign, as well as a list of the interview topics, including: changes to sexuality and intimacy; support received; and experiences of communication and information provision about sexuality with health professionals. All of the interviews were transcribed verbatim.

Analysis

Quantitative analysis of closed responses

Univariate analyses were conducted to compare women and men on each of the socio-demographic variables of interest separately for PWC and PPWC. For the continuous variable age, one-way ANOVA were conducted with gender as the grouping variable, and the chi-square test for independence used for frequency data. The Fisher's exact test (FET) was performed upon categorical data to test differences within gender and cancer classification groups on reports of discussion of sexual concerns with a health professional, wanting a discussion of sexuality with a health care professional, and satisfaction with discussion of sexuality with a health professional. To allow for dichotomous analysis and facilitate interpretation, ratings of satisfaction with discussion of sexuality were recoded into 'Satisfied or very satisfied' and 'Neither satisfied nor dissatisfied, not satisfied or not at all satisfied' reflecting the direction and meaning of the original Likert scale. In these analyses, the FET calculates the exact probability of significant differences in the reported assignments of women and men or people with a sexual cancer (breast, gynaecological, prostate, testicular) or non-sexual cancer (all other cancer types). The chi-square test for independence was used for frequency data associated with who had initiated discussion about sexuality. An alpha level of 0.05 was used for all statistical tests conducted independently for the PWC and PPWC samples.

Qualitative analysis of open-ended survey response and interviews

The analysis of the open-ended survey responses and interview accounts was conducted using thematic analysis (Braun & Clarke 2006). This process involved members of the research team reading through the responses in an 'active way' (Braun & Clarke 2006) to search for patterns and themes in and across the data about communication and information provision about sexuality with health professionals. After discussion, we then re-read all the relevant qualitative data to generate initial codes including: 'good support offered'; 'more discussion needed'; 'partners need more support'; 'waste of time'; 'talking to expert was helpful'; 'relational issues'. The entire qualitative data set was then organised and coded using QSR NVivo software, a package that facilitates organisation of qualitative data. Codes were grouped into higher order themes; a process that involved checking for emerging patterns, variability and consistency, and making judgements about which codes were similar and dissimilar. At this stage, we

re-labelled a number of key higher order themes by identifying the 'essence' (Braun & Clarke 2006) of each theme. The higher order themes relevant for this paper are: 'what was helpful/unhelpful from health professionals'; 'active in seeking own support/information'; 'onus is on health professional to raise the issue of sexuality'; 'feeling empowered to talk about sexuality'; and 'feeling let down by health professionals'. The thematically coded data was then collated and reorganised through reading and re-reading, allowing for a further refinement and review of themes. In this final stage, four central themes were developed: 'Discussing sexuality with health professionals'; 'Initiating discussions of sexuality'; 'Satisfaction with discussions of sexuality'; and 'Seeking information about sexuality from other sources'. Demographic information is provided for longer quotes; but is omitted from shorter quotes to enhance readability. Pseudonyms are used in the presentation of data to maintain anonymity.

RESULTS

Descriptive data

Table 1 presents the sample demographics by gender for the PWC and PPWC samples, for both sexual cancers (breast, gynaecological, prostate, testicular) and non-sexual cancers (all other cancer types). Ethnicity profile and relationship status did not differ between women and men PWC. The majority identified as from an Anglo-European-Australian background, and as being currently partnered and living together. However, women were significantly younger, 50.7 versus 61.1 years old, were more likely to identify as heterosexual, 96.7% versus 91.1%, and were more likely to report a sexual cancer, 89.3% versus 78.3%. For the PPWC sample, partner age, ethnicity profile, relationship status, sexual identity, and sexual or non-sexual cancer classification, did not differ by gender. PPWC were on average 54 years old, the majority identified as from an Anglo-European-Australian background, as being currently partnered and living together and heterosexual. The range and proportion of cancer type classifications for PWC and PPWC can be seen in Table 1.

Discussing sexuality with health professionals

For the PWC and PPWC samples, there was a significant difference between women and men and sexual and non-sexual cancer types in whether a discussion of sexual concerns had occurred with a health care professional (Tables 2 and 3). Such a discussion was significantly more likely to take place for men PWC (67.8%) than women

Table 1. Sample characteristics by gender for people with cancer (PWC) and partner of people with cancer (PPWC) samples

	Women		Men		Test for group difference	Significance	Effect size
	<i>n</i>	M (SD)	<i>n</i>	M (SD)			
Continuous data	<i>n</i>	%	<i>n</i>	%	F	<i>P</i>	η^2
Frequency data	<i>n</i>	%	<i>n</i>	%	χ^2	<i>P</i>	ϕ
PWC							
Patient age	535	50.7 (10.9)	122	61.1 (14.3)	79.01	<0.001	0.108
Ethnicity					0.51	0.774	0.028
Australian/White European	508	95.7	114	94.2			
Asian	14	2.6	4	3.3			
Other	9	1.7	3	2.5			
Cancer type					519.19	<0.001	0.364
Breast	425	80	–	–			
Gynaecologic	45	8.5	–	–			
Prostate	–	–	87	72.5			
Genitourinary other)	4	0.8	7	5.8			
Haematological/blood	23	4.3	14	11.7			
Digestive/gastrointestinal	11	2.1	4	3.3			
Neurologic	6	1.1	4	3.3			
Skin	8	1.5	2	1.7			
Other*	9	1.7	2	1.7			
Cancer classification					10.52	0.001	0.127
Sexual cancer type	474	89.3	94	78.3			
Non-sexual cancer type	57	10.7	26	21.7			
Relationship status:					3.12	0.374	0.032
Partnered – living together	414	77.4	96	78.7			
Partnered – not living together	34	6.4	10	8.2			
Not in a relationship	76	14.2	16	13.1			
Other/not specified	11	2.1	–	–			
Sexual identity					405.16	<0.001	0.858
Heterosexual	434	96.7	92	91.1			
Non heterosexual	15	3.3	9	8.9			
PPWC							
Partner age	87	54.1 (13.5)	61	54.8 (11.1)	0.11	0.738	0.001
Ethnicity					0.85	0.653	0.056
Australian/White European	82	97.6	57	95.0			
Asian	1	1.2	2	3.3			
Other	1	1.2	1	1.7			
Cancer type					60.10	<0.001	0.297
Breast	4	4.6	29	48.3			
Gynaecologic	4	4.6	9	15			
Prostate	35	40.2	2	3.3			
Genitourinary other)	6	6.9	–	–			
Haematological/blood	15	17.2	10	16.7			
Digestive/gastrointestinal	11	12.6	6	10.0			
Neurologic	2	2.3	1	1.7			
Skin	2	2.3	1	1.7			
Other*	8	9.2	2	3.3			
Cancer classification					1.60	0.207	0.104
Sexual cancer type	49	56.3	40	66.7			
Non-sexual cancer type	38	43.7	20	33.3			
Relationship status					0.12	0.896	0.011
Partnered – living together	79	90.8	55	90.2			
Partnered – not living together	8	9.2	6	9.8			
Sexual orientation					36.16	0.525	0.086
Heterosexual	79	90.8	55	90.2			
Non heterosexual	8	9.2	6	9.8			

Other includes: respiratory/thoracic, head & neck, various, each less than 1%.

Table 2. Ratings of discussions of sexuality with a health care professional (HCP) by gender and cancer classification for people with cancer (PWC)

Item	Women		Men		Test for group difference			Sexual cancer		Non-sexual cancer		Test for group difference		
	<i>n</i>	%	<i>n</i>	%	χ^2	<i>P</i>	ϕ	<i>n</i>	%	<i>n</i>	%	χ^2	<i>P</i>	ϕ
Discussion of sexual concerns with a HCP					24.74	<0.001	0.197					8.62	0.004	0.117
Yes	220	42.5	80	67.8				272	49.3	25	31.6			
No	298	57.5	38	32.2				280	50.7	54	68.4			
Wanting a discussion of sexuality with a HCP					9.52	0.003	0.157					0.73	0.409	0.044
Yes	157	47.0	37	69.8				165	51.1	28	45.2			
No	177	53.0	16	30.2				158	48.9	34	54.8			
Who initiated discussion					2.93							4.60		
Health care professional	56	25.2	19	24.1				70	25.1	3	11.5			
Self	144	64.9	48	60.8				170	62.5	21	80.8			
Partner	5	2.3	1	1.3		0.403	0.099	5	1.8	1	3.8		0.204	0.124
Self & partner	17	7.7	11	13.9				27	9.9	1	3.8			
Satisfaction with discussion					6.66	0.010	0.165					0.87	0.353	0.094
Satisfied or very satisfied	96	41.2	48	58.5				126	44.2	15	55.5			
Neither satisfied nor dissatisfied; not satisfied; or not at all satisfied	137	58.8	34	41.5				159	55.8	12	44.5			

Table 3. Ratings of discussions of sexuality with a health care professional (HCP) by gender and cancer classification for partners of people with cancer (PPWC)

Item	Women		Men		Test for group difference			Sexual cancer		Non-sexual cancer		Test for group difference		
	<i>n</i>	%	<i>n</i>	%	χ^2	<i>P</i>	ϕ	<i>n</i>	%	<i>n</i>	%	χ^2	<i>P</i>	ϕ
Discussion of sexual concerns with a HCP					5.49	0.024	0.196					5.56	0.022	0.198
Yes	40	47.1	16	27.6				41	47.1	15	27.3			
No	45	52.9	42	72.4				46	52.9	40	72.7			
Wanting a discussion of sexuality with a HCP					6.98	0.012	0.274					0.28	0.675	0.056
Yes	29	59.2	14	31.8				25	48.1	17	42.5			
No	20	40.8	30	68.2				27	51.9	23	57.5			
Who initiated discussion					2.66							5.48		
Health care professional	10	25.0	5	31.2				11	27.5	4	25.0			
Self	7	17.5	1	6.2				4	10.0	4	25.0			
Partner	12	30.0	3	18.8		0.447	0.218	9	22.5	6	37.5		0.140	0.313
Self & partner	11	27.5	7	43.8				16	40.0	2	12.5			
Satisfaction with discussion					0.04	0.765	0.333					0.19	0.566	0.221
Satisfied or very satisfied	22	52.4	9	60.0				23	57.5	17	42.5			
Neither satisfied nor dissatisfied; not satisfied; or not at all satisfied	20	47.6	6	40.0				8	47.1	9	52.9			

PWC (42.5%). In contrast, a higher proportion of women PPWC (47.1%) indicated that discussions of sexual concerns had occurred with a health professional compared to men PPWC (27.6%). Across the sexual and non-sexual cancers, the majority of PWC and PPWC indicated that a discussion of sexuality had not occurred with a health care professional, although the magnitude of this proportion was significantly higher for the non-sexual cancers (68.4% for PWC; 72.7% for PPWC) compared to sexual cancers (50.7% for PWC; 52.9% for PPWC).

Participants who reported *not* being involved in a discussion of sexuality were asked if they would have liked a health professional to raise the issue, with significant gender differences appearing in the reports (Tables 2 and 3). The majority of men PWC (69.8%) indicated that they would like such a discussion to occur, whereas the majority of women PWC (53%) did not want the same. In contrast, among the PPWC sample, the majority of men (68.2%) indicated that they did not want a discussion of sexuality with a health care professional compared to

59.2% of women who indicated that they did want such a discussion. No significant differences were found between the sexual and non-sexual cancer types, with relatively equal proportions either wanting or not wanting a discussion with a health care professional across the PWC and PPWC samples (Tables 2 and 3).

Initiating discussions of sexuality

Reports of who had initiated discussions of sexuality with health care professionals did not differ according to gender or cancer classification type across the PWC and PPWC samples as seen in Tables 2 and 3. Men and women PWC were most likely to initiate discussion at 60.8% and 64.9%, respectively, with health care professional initiated discussions reported by 24.1% of men and 25.2% of women PWC. For the PPWC sample, the reported initiators of discussions about sexuality were more evenly distributed amongst health care professional, self, partner and self and partner for both men and women. A similar profile was observed for the sexual and non-sexual cancer types. The majority of PWC sexual (62.5%) and non-sexual (80.8%) participants indicated that they had initiated discussion of sexuality with a health care professional, whereas for PPWC, the reported initiators of discussions about sexuality were more evenly distributed and did not significantly differ between cancer types.

The finding that many participants took up an active role in initiating a discussion of sexuality with a health professional was evidenced further in the qualitative accounts, with some accounts suggesting that once participants raised the issue of sexuality, the results were positive. For example, Matthew 'brought up the stuff around sexual function myself'; however, his oncologist 'handled it really well. He was really, really good with all of that and very understanding' (56 years, PWC, gay relationship, non-sexual cancer). Similarly, Heather commented: 'She (oncologist) and I are quite okay discussing it, she doesn't necessarily ask, but if I talk about it then she'll respond to the questions' (49 years, PWC, heterosexual relationship, sexual cancer).

However, the majority of qualitative participant accounts clearly positioned the onus on health professionals to raise the issue, with participants reportedly disappointed if sexual changes were not raised. For example: 'This issue was not given any significance by my oncologist/surgeon – maybe they could have suggested resources instead of me having to find it'; 'I am in my mid-50s. Not a single health professional I have ever consulted throughout my life has raised sexuality issues. No questions. No acknowledgement'. Many partners also

reported receiving no information or advice about changes to sexuality from health care professionals, feeling excluded from discussions about sexuality as a result: 'I haven't had a chance to discuss this with anybody', 'No-one made contact with me to offer suggestions of how to manage changes or how I was dealing with my own feelings and reactions'.

In addition, a large proportion of PWC and PPWC reported that they were too embarrassed to ask health professionals for help, mentioning: 'I didn't seek any outside help, I think I would have been embarrassed'. Some avoided health professional discussions, describing help as 'waste of time', hoping 'things would get better', or that with 'less medication my libido will return'. For many others, having to initiate the discussion themselves was a significant obstacle, taking 'a lot' to overcome, as exemplified by Della:

Cause it really took me a lot to go in and talk to my doctor about having a sexual problem [chuckles]. It, it took me a lot, and I even said to her, 'Oh my God, I've done it,' you know. I said 'I've actually come in and spoken about it,' you know. And I felt really good because it just broke that barrier. (65 years, PWC, heterosexual relationship, non-sexual cancer)

Satisfaction with health professional discussions about sexuality

Ratings of satisfaction with discussions of sexuality with health care professionals differed significantly between the genders for PWC. For men PWC, the majority (58.5%) reported that they had been satisfied or very satisfied with the discussions, compared to majority of women PWC (58.8%) indicating that they had been neither satisfied nor dissatisfied, not satisfied, or not at all satisfied with these discussions. For the PPWC sample, there was no significant difference between the gender groups, with majority of PPWC men (60%) and women (52.4%) indicating that they had been satisfied or very satisfied with the discussions of sexuality with a health care professional. Ratings of satisfaction with discussions of sexuality with health care professionals did not differ significantly between the sexual and non-sexual cancer types, with rating more evenly distributed across cancer types for the PWC and PPWC samples.

There were many qualitative accounts where participants positioned their discussion of sexuality with health professionals as both positive and helpful – characterised by health professional support and understanding, and the provision of adequate information and advice: 'My oncologist was understanding, helpful and comfortable talking

about this subject'; 'I found my oncologist very helpful and supportive'. In many cases, these participants positioned health professionals as 'great', 'wonderful', 'personable', 'absolutely fantastic' and 'excellent'. A few participants reported that their health professional would 'move heaven and earth to try and solve' their sexual concerns, that 'no subject was outside the scope of [his] experience', and that the issue of sexuality was considered 'important' and treated 'with great respect'. However, the majority of PWC and PPWC qualitative accounts described their discussion of sexuality with health professionals as negative and unhelpful. In particular, the majority of participants reported experiencing a lack of information, advice, and support about sexuality, as well as feeling that sexuality was trivialised in relation to 'legitimate' medical concerns. This left many participants feeling 'neglected' and 'abandoned', drawing on rich hyperbole to position health professionals as 'not interested', 'clinical and soulless', 'ignorant', 'disgraceful', 'unsatisfactory' and 'dismissive'. For example, as some participants reported: 'The attitude of my oncologist that I was lucky to be alive and that any sexual problems were minor'; 'I was told it was something I would just have to live with. A statement like that is so depressing'; 'I found their attitude of "just deal with it" to be totally unsatisfactory'.

Other participants reported that even when they attempted to raise sexual concerns with a health professional this was not met with an adequate response: 'the specialist simply stated that he was not interested in my sexual functioning after the surgery, but that he was more interested in removing the cancer and giving me another 30 or more years' (PWC, 57 years, male, heterosexual relationship, prostate). As Helen mentioned:

He was just saying, 'Well you've, you've had surgery, you'll be alright afterwards'. 'My GP, I talked to him more about the fact that I'd gone through a premature menopause. He shrugged his shoulders and he said, 'Well, that's to be expected', and I asked for something and he gave me Ovestin cream. There was no other comment made and I was never asked about it again. (Helen, 64 years, PWC, non-sexual cancer, heterosexual relationship)

A number of participants also pointed out that 'fundamental' issues, including discussion and advice about ways of maintaining sexuality post cancer, were often ignored:

After treatment, you may have difficulty with erections and, you know, you might need to use sex aids and stuff like that. Well, they don't even talk about the

fact that – that, um, you'll – you'll probably lose a lot of your sex drive, and that sex may not be as – as pleasurable as it used to be, in fact, it may even be slightly painful [laughs]. (. . .) So I'm just – it's such a fundamental thing. I can't believe that – that the – the level of, sort of, ignorance and – and the lack of – of, um, discussion that occurs in the – in this area. (Stuart, 60 years, PWC, sexual cancer, gay relationship)

Seeking information about sexuality from other sources

When health professionals were seen as not providing an adequate discussion of sexuality, many PWC and PPWC reported sourcing their own information about sexual changes, via booklets, the internet, and literature from cancer agencies. As one participant explained:

When I first went to my breast surgeon for a follow-up and discussed having my ovaries removed, he said yep we'll just take them out. I became very upset, I was wanting further information and none was provided. I had to do research myself. (PWC, 35 years, female, heterosexual relationship, breast)

Participants also mentioned seeking information from support groups and intimate partners, with accounts including: 'talked to friends in same boat at breast cancer support group'; 'My husband is the most helpful – he is very patient and supportive and doesn't pressure me'. In some cases, participants who did not engage in a discussion about sexuality with a health professional reportedly changed their clinical team, to ensure their sexual needs and concerns were addressed, saying: 'I wouldn't be going back to him', and 'I have since found new doctors'. For example, Emma recounted that whilst her oncologist 'might be good with a knife', when 'it comes to communication skills, it was just disgusting'. In response to her experience of unmet sexual needs, she went on to say that she 'realised' that she could 'manage' and actively 'choose' her own 'team' of health professionals of which she was the centre:

If he doesn't listen to me, if he doesn't have any respect for me, he's not going to manage me, and from that point on too, I realised that I had to manage myself, and this concept of, you know patient-centred care and, you know, the patient is actually the centre of the team, and then I realised that I had to choose my team. (52 years, heterosexual relationship, PWC, sexual cancer)

In some instances, the desire to change health care professional stemmed from the manner in which sexuality

was raised, rather than whether it was raised *per se*. For example, Ewan talked about an instance where, in response to his wife asking the urologist about post-radiotherapy impotence, the response was 'Oh, they'll fry the nerves, you know you'll never get an erection again because all your genital nerves will be fried.' For Ewan, this 'was a very, very silly thing to say', and he went on to explain that:

I thought for him to say that, and use the word fry, I wouldn't go back to that urologist because of that, that's the last time I saw him. If I'm referred to urologist again, I wouldn't be going back to him (64 years, heterosexual relationship, sexual cancer).

DISCUSSION

The aim of this study was to examine whether people with cancer and partners have engaged in a discussion with a health professional about sexuality, and how such interactions are constructed and experienced. We found that whilst many people with cancer and partners had engaged in a discussion about sexuality with a health professional, this was not the case for the majority. This confirms previous research (Stead *et al.* 2003; Emslie *et al.* 2009; Flynn *et al.* 2012), and lends support to the notion that people with cancer and partners may have unmet sexual needs (Hill *et al.* 2011).

Men with cancer and women partners were most likely to report having had a discussion about sexuality with health professionals, and to report wanting a health professional to raise the issue of sexuality – confirming previous research (Rassmusson *et al.* 2013). This finding potentially highlights the ways in which dominant discourses of gender and heterosexuality can shape experiences of discussions about sexuality with health professionals (see also Ellingson & Buzzanell 1999). That is, heterosexual participants – the majority of our sample – and health professionals may be privileging men's sexuality, with changes to men's sexuality post-cancer positioned as in more need of 'fixing', or as more 'important', than changes to women's sexuality. In this vein, Wendy Holloway (1989) alerted us to the male sex drive discourse in which men are constructed as 'driven by the biological necessity to seek out (heterosexual) sex' (page 54). Men's sexuality is positioned as a symbolic expression of manhood (Fergus *et al.* 2002), with a phallogocentric notion of male sexuality standing as central to hegemonic masculinity (Connell 1987; Wall & Kristjansen 2005; Potts *et al.* 2006). Thus, the onset of men's sexual 'dysfunction', especially erectile dysfunction after cancer, problematises the 'normally "silent" male body' (Kelly 2009), resulting

in men with cancer being seen to be in particular need of assistance in the form of erectile medications to fix 'troubled' (Loe 2001) or 'precarious' masculinity (Gurevich *et al.* 2004; Gilbert *et al.* 2013). In contrast, women's inclusion in discussions of sexuality by health professionals may be determined largely by virtue of their role as a partner in a heterosexual relationship (see also White *et al.* 2013). This is despite evidence that women with cancer experience a range of significant sexual changes post cancer (Bergmark *et al.* 1999; Basson 2010; Perz *et al.* 2014), as well as negative body image or feelings of sexual un-attractiveness (Bertero & Wilmoth 2007; Plotti *et al.* 2011) and loss of femininity (Archibald *et al.* 2006). In addition, women partners experience changes to their own sexuality, including reduced frequency of sex, reduced desire, arousal and orgasm (Perz *et al.* 2014), as well as a post-cancer re-positioning of their identity from that of sexual partner to an asexual nurse/carer (Gilbert *et al.* 2009).

Our findings lend support to the notion that women with cancer may be particularly lacking in support and information from health professionals about sexual changes (Gamel *et al.* 2000), and thus potentially have more unmet sexual needs than men with cancer (Flynn *et al.* 2012). At the same time, we found that the majority of women PWC and men PPWC reported not wanting to have a discussion about sexuality with health professionals. As previous research on women with breast cancer has shown, the majority wanted to discuss sexuality with their partner rather than with a health professional, with such couple communication positioned as an important coping strategy (Ussher *et al.* 2013a). Further research is needed to explore why men PPWC may not want to discuss sexuality with health professionals. One possible explanation is that coital sex is more likely to continue in heterosexual couples where the woman has cancer, compared to couples where the man has cancer, even if the woman experiences pain or absence of desire (Jensen *et al.* 2004; Hawkins *et al.* 2009). Male partners may therefore not position the sexual relationship as problematic, and in need of professional intervention.

The finding that partners are more likely to be absent in any discussion about sexuality is problematic, in the light of research showing that intimate partners have reported worsened sexual functioning after cancer, independent of the survivor's experience (Reese 2011). Indeed, partners have reported experiencing a range of sexual changes post cancer, including decreased frequency of sex, the complete cessation of sexual relationship, tiredness, lack of sexual spontaneity, reluctance to initiate sex, as well as a repositioning of their partner as an asexual sick patient

(Hawkins *et al.* 2009). These changes can leave partners feeling frustrated, sad (Gilbert *et al.* 2009), and unable to assist in sexual and emotional health of their partner with cancer (Rasmusson & Thome 2008; Emslie *et al.* 2009; Kisinger *et al.* 2011). Although there is evidence to suggest that the majority of partners receive some form of information from patients with whom they are in an intimate relationship (Rees & Bath 2000), it is important to bear in mind that the informational needs of patients and their partner are not necessarily identical in content and quantity (Rees *et al.* 1998), and that patients tend to be more satisfied with information received than partners (Salander & Spetz 2002). In addition, the idea that partners should have to rely on patients for information, assumes that patients with cancer are being provided with the opportunity to discuss sexuality with a health professional in the first instance; as the findings of the present study show, this is often not the case. It also assumes that patients with cancer will 'pass' this information on; however, the passing on of information between couples is contingent upon the level of couple communication (Rees & Bath 2000), meaning that those lacking in couple communication may be especially likely to have unmet sexual needs (Ussher *et al.* 2013b).

People with cancer and partners living with a non-sexual cancer were significantly less likely to report having a discussion of sexuality with a health professional than those with a sexual cancer, confirming previous research (Hautamäki-Lamminen *et al.* 2013). However, there were no differences across sexual and non-sexual cancers for whether participants would like sexuality to be raised by a health professional – supporting the contention that discussions and information about sexuality are needed across cancer types (Hordern & Street 2007a; Perz *et al.* 2013). This stands in contrast to the focus of most systematically evaluated interventions to ameliorate the impact of sexual changes, which have largely focused on sexual and reproductive cancers (Miles *et al.* 2007). However, as our findings suggest, it is not only cancers that affect sexual or reproductive sites of the body that impact on sexuality, and there is a need to critically question discursive constructions of the bodily boundaries that are considered 'sexual sites' so that those experiencing a cancer in a 'non-sexual' site of the body, also receive information and support about sexual changes after cancer.

When a discussion of sexuality did take place with a health professional, men and women with cancer were most likely than health professionals to initiate such a discussion. For some participants the initiation of a discussion of sexuality with a health professional was positioned positively, and resulted in the provision of

information, advice, support and feelings of empowerment. This finding stands in contrast to the vast majority of research into communication and information about post-cancer sexuality, which has tended to position patients as relatively passive vis-à-vis health professionals. In fact, it has been argued that when health professionals fail to raise the issue of sexuality, sexuality remains undiscussed because patients 'trust in the expert' (Hordern & Street 2007b), or tend not to initiate a discussion of sex unless health professionals provide the opportunity (Ananth *et al.* 2003). In addition, previous reports suggest that people with cancer believe that if sexuality was 'important', health professionals would have raised it with them (Hordern & Street 2007b) – a position that is not difficult to understand given the dominant discourse in popular culture and the media that health professionals, in particular medical doctors, are experts and authorities (Lupton & McLean 1998). However, there is a growing focus in cancer care on a patient-centred approach to health communication, with the patient positioned as an active part of the health care 'team' (Brown *et al.* 1999), which means it is considered to be a shared responsibility of both the patient and health professional to raise the issue of sexuality (Hordern & Street 2007b) – a position adopted by some participants in the present study.

This notwithstanding, approximately one quarter of all participant groups (PWC, PPWC, men and women, sexual and non-sexual cancers) put the onus on health professionals to raise the issue of sexuality and were disappointed when the issue was not raised. Indeed, as the majority of participant accounts revealed, when health professionals failed to initiate a discussion, many people with cancer and partners who are shy, embarrassed, or arguably take up the role of the passive patient who is complicit in the silencing of sexuality, are excluded. As evidence shows, being provided with information is essential for people with cancer and partners to feel they have some control over the situation (Lavery & Clarke 1999), and assists in ensuring that all sexual and intimacy does not cease post cancer (Hawkins *et al.* 2009). The PLISSIT model (Permission, Limited Information, Specific Suggestions, Intensive Therapy; Annon 1981) is a useful starting point for health professionals to provide the opportunity to discuss sexuality, and allow people with cancer and partners to take up or engage in the discussion (White *et al.* 2013). Such an approach positions sexuality in the context of cancer as legitimate, and potentially avoids providing information to people with cancer and partners that is not necessarily wanted or relevant (Rasmusson & Thome 2008).

Confirming previous research (Flynn *et al.* 2012), we found that when sexuality was discussed with a health

professional, the majority of men with cancer were either satisfied or very satisfied with the discussion, with many participants feeling supported, and positioning health professionals very positively. This highlights the positive outcomes for people with cancer and partners when health professionals 'get it right' (Hordern & Street 2007a). However, many participants, including the majority of women with cancer and a considerable proportion of partners, reported being dissatisfied with the discussion of sexuality, as was also evident in the qualitative accounts on this issue. An overwhelming number of qualitative accounts indicated dissatisfaction with, and feeling neglected by, health professionals – for either failing to raise the issue of sexuality, or failing to provide adequate information. This finding supports previous research in this area which suggests that some people with cancer report that their interactions and experiences with health professionals when discussing sexuality after cancer are uncaring (Halldorsdottir & Hamrin 1997), or characterised by incompetence and neglect (Frankel 1995). Patient castigation may stem from the dominant socio-medical construction of health professionals as humane and competent experts (Foucault 1989). When health professionals are perceived by people with cancer and partners to be failing to fulfil this construction, they become subject to extreme condemnation and are positioned as behaving in a way that is antithetical to the socio-medical construction of humane experts. This finding emphasises the need for health professionals to provide the opportunity to discuss sexuality, and the importance of good communication skills and training for both new and established health professionals.

When participants in the present study were not included in a discussion with a health professional or received inadequate information about sexuality, many sought out their own information via booklets and the internet, attending support groups, talking to their partner, or changing health professionals; highlighting the importance of sexuality to these PWC and PPWC. However, it is important to note that people with cancer may not know where to look for information about sexuality or that existing information does not always meet their needs (Ussher *et al.* 2013a).

It has been previously reported that absence of discussion with health professionals is linked to a range of personal, patient-centred, and situational barriers, including a lack of health professional knowledge, confidence, or comfort, the positioning of some patients as asexual or disinterested in sexuality, as well as a lack of health professional time and privacy in a clinical context (Ussher *et al.* 2013c). Such a lack of discussion could also be due to

the 'fear of sexuality' in a clinical context, as the dominant discourse around sexuality has historically been one of silence and prohibition, with hospital spaces particularly asexualised (Dupras & Poissant 1987). The institutionalisation of this dominant discourse means that sexuality is often positioned as incompatible with the 'image of the good patient, described as quiet, docile and preoccupied with recovery or conserving his (*sic*) strength' (Dupras & Poissant 1987). According to this discourse, neither the patient nor the health professional should raise the issue of sexuality, resulting in a silencing and mystification of sex, and a subsequent lack of information and support about potential treatment side effects on sexuality and ways to manage these side-effects and other post-cancer sexual changes.

This study was limited insofar as the sample comprised English-speaking, and largely Anglo-Australian people with cancer and partners. Thus, we are unable to comment on the ways in which culture and class may also intersect to shape interactions with health professionals around the issue of sexuality. In addition, whilst we attempted to include a range of sexual identities in our sample, the majority of people with cancer and partners were heterosexual. Further research is needed to examine how cultural and sexual identity may impact information and support received from health professionals, as there is evidence that health professionals lack confidence in discussing gay and lesbian sexuality, or discussing sex with cultural minorities (Ussher *et al.* 2013c). We also had a greater number of PWC than PPWC, due to the difficulties in recruiting partners. Nonetheless, it is clear that health professionals are not initiating a discussion of sexuality with many people with cancer and partners, and that there are some groups for whom this discussion and subsequent information appears to be considered more relevant – namely people with sexual and reproductive cancers, men with cancer, and women partners. This means that a number of people are being excluded from discussions, contributing to unmet sexual needs. However, as the present study shows, when health professionals do engage in a discussion about sexuality, they are often considered to be supportive, by both people with cancer and partners. This highlights the important role that health professionals can play in ameliorating distress around post-cancer changes to sexuality. Indeed, there has been a growing body of research dedicated to assisting health professionals effectively initiate a discussion of sexuality in the context of cancer. Such research has suggested that health professionals could provide support by initiating a discussion of sexuality, and by providing adequate information about sexuality in a way that moves beyond a mere

biomedical approach to sexuality. This may involve adopting a range of specific techniques, including: validating sexual concerns; offering information about the potential impact of cancer and treatments on the sexual and intimate relationship; outlining a range of self and partnered sexual and intimate activities that are not limited to coital-sex; providing supportive resources (Syme *et al.* 2013), or providing referrals to people with cancer and partners for psycho-education (Gallo-Silver 2000). When implemented sensitively across the cancer journey – bearing in mind that people with cancer and partners are not a homogenous group – these techniques are central to understanding and meeting the sexual needs and concerns of people with cancer and partners.

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ACKNOWLEDGEMENTS

This research was funded by an Australian Research Council Linkage Grant, LP0883344, in conjunction with the Cancer Council New South Wales and the National Breast Cancer Foundation. We received in-kind support from Westmead Hospital and Nepean Hospital. The chief investigators on the project were Jane Ussher, Janette Perz and Emilee Gilbert and the partner investigators were Gerard Wain, Gill Batt, Kendra Sundquist, Kim Hobbs, Catherine Mason, Laura Kirsten and Sue Carrick. We thank Tim Wong, Caroline Joyce, Emma Hurst, Amy Dryden, Rosie Charter, Jan Marie and Chloe Parton for research support and assistance.

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