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Talking about sex after cancer: A discourse analytic study of health care professional accounts of sexual communication with patients

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There is consistent evidence that health care professionals (hcps) are not addressing the sexual information and support needs of people with cancer. Thirty-eight Australian hcps across a range of professions working in cancer care were interviewed, to examine constructions of sexuality post-cancer, the subject positions adopted in relation to sexual communication, and the ways in which discourses and subject positions shape information provision and communication about sexuality. Participants constructed sexual changes post-cancer in physical, psychological and relational terms, and positioned such changes as having the potential to significantly impact on patient and partner well-being. This was associated with widespread adoption of a discourse of psychosocial support, which legitimated discussion of sexual changes within a clinical consultation, to alleviate distress, dispel myths and facilitate renegotiation of sexual practices. However, this did not necessarily translate into patient-centred practice outcomes, with the majority of participants positioning personal, patient-centred and situational factors as barriers to the discussion of sex within many clinical consultations. This included: absence of knowledge, confidence and comfort; positioning sex as irrelevant or inappropriate for some people; and limitations of the clinical context. In contrast, those who did routinely discuss sexuality adopted a subject position of agency, responsibility and confidence.

Keywords: cancer; sexuality; health care professional; communication; discourse analysis

Introduction

It is widely acknowledged that cancer can result in significant changes to sexual well-being, resulting from a range of physical and emotional side effects of cancer and its treatments (Galbraith & Crighton, 2008; Gilbert, Ussher, & Perz, 2011; Traa, De Vries, Roukema, & Den Oudsten, 2012). There is much evidence that people with cancer and their partners want to discuss these changes with health care professionals, but they tend not to initiate such a discussion unless health professionals provide the

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opportunity (Ananth, Jones, King, & Tookman, 2003; Hawkins et al., 2009; Hordern & Street, 2007a). This has lent support to the conclusion that health professionals should be actively providing information about sexual well-being and routinely discussing sexuality in a holistic manner (McKee & Schover, 2001). This could include specific suggestions related to sexual positioning or the use of sexual enhancement products (Herbenick, Reece, Hollub, Satinsky, & Dodge, 2008), adjustment to changes and expansion of sexual repertoires (Archibald, Lemieux, Byers, Tamlyn, & Worth, 2006), as well as information for partners (Hawkins et al., 2009). Health professionals can also directly challenge the misconception that sexuality is 'frivolous' during cancer, thus 'giving permission' for couples to talk about sex and be sexually intimate (Schwartz & Plawecki, 2002, p. 3).

However, there is evidence that the sexual information and support needs of people with cancer are not being met (Katz, 2005), with open communication about post-cancer physical and sexual changes (Landmark, Böhler, Loberg, & Wahl, 2008), the effects of treatments on sexuality and body image (Ussher, Perz, & Gilbert, 2013), relationship issues (Hordern & Street, 2007b), and psychological support (Landmark et al., 2008), standing as notable areas of unmet need. When sexuality is discussed, the focus is primarily on erectile functioning, menopause, contraception and fertility (Hordern & Street, 2007a), with 'sex' constructed within a narrow heterocentric framework (Hyde, 2007). This narrow focus and absence of information or communication can leave people with cancer and their partners struggling to cope with changes to sexuality (Landmark et al., 2008), feeling 'let down' by health care professionals (Hordern & Street, 2007a), or feeling as though their sexual needs and concerns are not legitimate (Butler, Banfield, Sveinson, & Allen, 1998).

Health care professionals are, however, increasingly recognising the significance of sexual changes and concerns post-cancer. For example, it has been found that the majority of health professionals position sexuality as an important issue (Haboubi & Lincoln, 2003; Lindau, Surawska, Paice, & Baron, 2011; Stead, Brown, Fallowfield, & Selby, 2003), recognise the role of sexual well-being in post-cancer quality of life (Tan, Waldman, & Bostick, 2002), understand the extent to which illness and treatment impacts on sexuality (Saunamäki, Andersson, & Engström, 2010) and position themselves as responsible for information provision (Hautamaki, Miettinen, Kellokumpu-Lehtinen, Aalto, & Lehto, 2007; Jefford et al., 2008). Sexual communication models such as PLISSIT (Annon, 1976) and BETTER (Mick, Hughes, & Cohen, 2004) have been developed (see also Hughes, 2000; Katz, 2005), and clinical practice guidelines published (Cancer Australia, 2003, 2004, 2012; National Centre for Gynaecological Cancers, 2011), to provide further recognition of the importance of sexuality in the context of cancer and the need for health professionals to take responsibility for initiating discussions around this issue.

Despite this recognition, research has consistently identified a range of barriers to health professional information provision and communication about sexuality. Most of this research has focused on structural constraints, such as a lack of time, experience, privacy or education (Hautamaki et al., 2007; Hordern & Street, 2007b; Stead et al., 2003); and personal barriers, including role ambiguity (Jenkins, Fallowfield, & Poole, 2001), concern about over-involvement in the non-medical aspects of patient's lives (Hordern & Street, 2007b; Lindau et al., 2011) and vulnerability or embarrassment (Hordern & Street, 2007b; Meerabeau, 1999; Stead et al., 2003). However, with the

exception of the work of Hordern and Street, little attention is paid to the ways in which sociocultural constructions of sexuality and illness, as well as 'how and when to speak to a patient and what shall remain taboo' (Hordern & Street, 2007b, p. 1706), also inhibit information provision and communication.

For example, there is evidence that some health professionals do not provide information or communicate about sexuality with their older patients, adopting a discursive construction of older people as asexual or likely to be offended if the issue is raised (Gott, Galena, Hinchliff, & Elford, 2004; Hordern & Street, 2007b). Assumptions about 'normal' sexuality are also made on the basis of gender, ethnicity, diagnosis, partnership status and sexual orientation (Gott et al., 2004; Hordern & Street, 2007b), resulting in the neglect of the needs of significant numbers of individuals. At the same time, sexual communication models such as PLISSIT operate under the assumption that if health professionals are educated about the importance of sexuality, and provided with guidelines on how to communicate about sex in the context of cancer, then they will do so (Hordern & Street, 2007b). However, there is often a disjuncture between knowledge of sexuality and clinical practice in discussing such issues (Haboubi & Lincoln, 2003), which cannot be fully explained by structural or personal barriers. Another issue is that these models and strategies are underpinned by a 'one size fits all' approach, which assumes a universality of context and health professional-patient interactions. This neglects to account for the fact that health professionals are often engaged in negotiating information provision and communication on a case-by-case basis, and in a context that is shaped by an interaction of structural, personal and sociocultural constraints.

This study adopted a material-discursive-intrapsychic perspective (Ussher, 2000) to examine how health professionals construct and negotiate sexual health concerns in the context of cancer. This perspective acknowledges that there is an interaction between material (structural), discursive (sociocultural constructions) and intrapsychic (personal) barriers, and that this interaction provides the context in which sexual communication is negotiated in the context of cancer. We utilised a qualitative methodology and a post-structuralist discourse analytic perspective to analyse the data, which examines the role of discourse in the constitution of subjectivity and social practice, whilst also acknowledging the material conditions which influence such experiences, and the role of discourse in wider social processes of legitimation and power (Gavey, 1989). In this context, 'discourse' refers to a 'set of statements that cohere around common meanings and values ... (that) are a product of social factors, powers and practices, rather than an individual's set of ideas' (Hollway, 1983, p. 231). Language is not viewed as simply descriptive of 'real' phenomena, but rather as constitutive of what we come to think of as reality. The focus of analysis is thus on the subject positions made available through discourse, conceptualising the accounts of individuals as discursive productions, rather than as reflections of their 'true' experience, accurate or otherwise (Gavey, 1989, p. 466). The research questions addressed in this study were: 'How do health professionals discursively construct sexuality in the context of cancer?'; 'What subject positions do health professionals adopt in relation to sexual communication?' and 'What do health professionals position as barriers to sexual communication within the context of cancer?'

Method

Participants and recruitment

This study was part of a larger mixed-method project examining changes to sexuality after cancer from the perspective of people with cancer, their partners and health professionals (author ref). Participants involved in the present study included Australian health professionals working in cancer who responded to an invitation circulated through professional networks. Thirty-eight people took part in semi-structured interviews – 33 women and 5 men (average age 48), comprising 9 doctors, 11 nurses, 10 psychologists and 8 social workers, across a range of cancer specialities: 36% general; 32% gynaecology; 13% haematology; 10% breast; 3% colorectal; 3% neurological and 3% urological. A multidisciplinary team of academics and clinicians working in oncology, including two individuals (a person with cancer and a partner) nominated by a cancer consumer organisation, acted as an advisory group, commenting on the design, method and interpretation of results. We received ethics approval from the University Human Research Ethics Committee.

Qualitative interviews and analysis

One-to-one semi-structured interviews were conducted to examine health professionals' constructions of sexuality in the context of cancer, and their constructions and experiences of communicating about sexuality with patients and their partners. The interviews were audio-recorded ranged in duration from 45 to 90 min, and were conducted on a telephone or face-to-face basis by two trained interviewers. Thematic decomposition (Stenner, 1993) was adopted to explicate the dominant themes within the data. This analytic technique combines discursive approaches with thematic analysis, situated within a broader post-structuralist discourse analytic approach (Gavey, 1989), and is informed by the notion that meanings are socially constituted through discourse. All of the interviews were transcribed verbatim. A subset of the interviews was then independently read and reread by each member of the research team to identify first-order codes associated with constructions of sexuality and sexual communication, such as 'impact of cancer on self and relationship', 'important information to communicate', 'talking about sex' and 'not talking about sex'. Each of these codes was then broken down into sub-codes, to provide a detailed map of the data. The entire data set was then coded using NVivo, a computer package that facilitates organisation of coded qualitative data. All of the coded data was then read through independently by two researchers, and then grouped into discursive themes, focusing on constructions of sexuality and barriers to sexual communication. This process involved checking for emerging patterns, variability and consistency, commonality across participants and for uniqueness within cases, in order to identify the discursive constructions of sexuality, and of sexual communication between health professional and patient, in the context of broader cultural discourse. The function these discourses served for health professionals was identified and attention paid to the subject positions made available through various discursive constructions of sex and sexual communication. The implications of discursive constructions of sex and sexual communication for practice were also examined, and attention paid to the consequences of taking up or resisting subject positions, in relation to barriers to sexual communication.

The results are presented in two sections: discursive constructions of sexuality in the context of cancer and constructions of barriers to health professional communication. Pseudonyms have been allocated to participants, and information about occupation and cancer speciality provided for each account (nurse; sw=social worker; Dr=doctor; psy=psychologist; gynae=gynaecological; haem=haematological and neuro=neurological).

Results

Discursive constructions of sexuality in the context of cancer adopted by health professionals

Pain, impotence, diminished libido and infertility: changes to the sexual body

The majority of health professionals constructed sexuality post-cancer as embodied changes resulting from cancer or cancer treatment. These physical changes were predominantly identified in cancers that affected the sexual or reproductive organs, such as gynaecological, breast or prostate cancer. This suggests the adoption of a bio-medical discourse, with sexuality conceptualised in terms of physical functioning, and the interruption of coital sex is categorised as dysfunction (Tiefer, 2004). In this vein, the impact of cancer treatment on the ability to engage in coital sex was positioned as one of the most significant changes to occur. For example, Jane (psy, general) described a patient whose sexual life was 'no go' because 'she has two bags – a urine bag and a colostomy bag and she's got massive scars, she's had her whole vagina removed so she's been stitched up'. The appearance of the genitals after surgery was also described as problematic by some, including Andrew (Dr, gynae) who said that 'the more problematic ones are the women with vaginal and vulval cancers, particularly if you've done extensive surgery, they look different, they feel different so that can affect both them and their partners'.

Cancer treatment was identified as the primary cause of sexual pain, resulting in vaginal dryness. Thus, Jennifer (sw, general) described radiotherapy to the vagina as having 'a *huge* impact', which 'almost in all situations has a negative impact definitely on sexual intercourse'. Chemotherapy following breast cancer was associated with similar effects, as Angela (nurse, general) described: 'women going through chemotherapy have gone into menopause and they're very dry'. Men with prostate cancer were also described as 'hugely' affected by sexual changes, with incontinence described as 'a big thing that goes along with the prostate surgery' (Janice, nurse, urology and neuro), and 'sexual dysfunction being really common' (Maree, psy, general).

In my experience the men especially with their prostate cancer, if they don't, some of them are not told until afterwards that they cannot have an erection. And their words to me have been, 'I would rather have died than had the surgery'. (Janice)

The sexual organs were not always positioned as central to constructions of physical changes to sexuality after cancer. Generalised pain resulting from cancer was identified as a factor that affects sexuality, as 'sex can't be pleasurable if you're experiencing pain' (Cassandra, sw, gynae), and 'with advanced disease, pain can make it really difficult for them to enjoy the kind of sex life they've had before' (Andrea, psy, urology).

Tiredness and fatigue were mentioned as ‘general oncological issues’ that can affect sexuality, resulting in ‘not feeling like it (sex) any more’ (Gail, Dr, general), because ‘by the time it’s night time really that would be the last thing that you have one bit of energy for’ (Jennifer, sw, general). Absence of desire, ‘lack of libido and unmatched libido’ were also described as a ‘really common problem’ (Maree, psy, general).

Changes in fertility status were discussed by a number of interviewees, with Paul (nurse, haem), saying ‘fertility’s probably one of the major issues that comes up all the time’. Infertility was positioned as ‘devastating’ by Renee (psy, gynae), in her work with cervical cancer patients:

Most often we’ve had the most devastating extreme reactions to fertility things, almost to the point where they just forget that they’ve even got cancer and they don’t care that they’ve got cancer; ‘I just want to be fertile? How am I going to get some eggs retrieved?’

These latter accounts reflect health professional’s acknowledgement that sexual well-being following cancer is influenced by an interaction of physical and psychological factors, which means that embodied changes are not the sole focus of concern.

Body image, identity and relationship concerns: psychological and relational aspects of sexual changes after cancer

Many of the health professionals constructed sexual changes post-cancer in psychological terms, drawing on a broader psychosocial discourse, which positions psychological and relational factors as central to well-being. For example, changes to body image were positioned as ‘very important for women with breast cancer’ (Annie, Dr, breast), and ‘a really common issue’ in terms of ‘body image disrupting sex, people’s sex lives’ (Maree, psy, general). This was described as resulting in women not ‘feeling feminine anymore’ (Colleen, nurse, general), or ‘feeling sexless’ (Cassandra, sw, gynae). Their partner’s reaction to physical changes to the body after surgery was positioned as a key factor in women’s body image concerns:

You have the scar from your mastectomy that you’ve got to look at every day. Some partners are really good and really supportive, other partners can cringe when you know a woman takes off her clothes because she is not as perfect as they remembered her. (Angela, nurse, general)

Whilst body image changes were predominantly positioned as a concern of women, they were also identified as an issue for some men with cancer. For example, Leanne (sw, haem) described seeing a patient who was ‘saying how he feels really unattractive at the moment because he looks awful ... and he is really worried how that is going to affect his sexual relationship’. Maree (psy, general) described ‘the blokes who lose their hair’ as being ‘devastated, because they’ve always been “Mr. Sexy”, the only one of the 60 year olds that kept their hair, and it all falls out ... and they really lose their sexual confidence’.

Whilst body image was commonly described as a concern ‘particularly with breast cancer’ (Lynette, psy, general), it was also acknowledged that ‘even women who have had bowel cancer or lung cancer can feel as sexually unattractive’ because ‘it’s really

feeling very changed within them I think' (Megan, psy, general). The sense of wanting to avoid being 'changed within' was identified as a factor in decisions to 'resist' life saving surgery, demonstrating the perceived impact of sexual identity concerns:

I've had people with cancer who will probably not have children anymore, they're 42, but then they're exceptionally resistant to having their uterus removed because it defines who they are. 'I feel like a woman if I have a uterus, and if I don't have it I just don't feel like a woman'. (Stephen, Dr, gynae)

Changes in identity resulting from disruptions to sexual functioning were also identified in men with cancer. Michele (sw, haem) described one man who felt that he was 'not a complete person anymore' because he was impotent: 'he was a real bloke and then devastated by cancer, but just that whole part of his identity had been taken away'. Ashley (psy, prostate and breast) said that men experience 'fear of disappointing their partner' and failing in 'their basic sense of a man, how a man should be', and as a result 'distance' themselves from sex.

A number of health professionals gave accounts of relationship disruption following the diagnosis of cancer, as 'it can actually destroy the affection between relationships' (Lauren, nurse, breast). One woman with breast cancer, who had 'lots of vaginal symptoms' was reported to have been told by her husband 'you're not a wife to me anymore', before he 'had an affair' which resulted in a deep 'sense of betrayal' (Annie, Dr, breast). In a similar vein, Gail (Dr, general) said 'I've had other patients who the husband has just turned around and said, 'Right. That's it. You've got cancer. I am leaving'. Even when relationships remained intact, health professionals reported patient anxiety related to fear of their partner having an affair, or feelings of guilt or shame associated with cancer. Renee (psy, gynae) reported that one patient said to her that 'I feel dirty and ashamed that I've got cancer', and that as a result, her sexual relationship with her partner was 'non-existent'. Ashley (psy, prostate and breast) said that women 'worry about pleasing their husband or partner, or feeling guilty that they're not the kind of woman that they used to be' following changes to fertility or ability to engage in penetrative sex, leaving the woman 'feeling worried about the needs of their partner not being satisfied'. Similarly, men could experience a change in 'their self esteem, their whole meaning in life. Their relationship then starts to split and they withdraw because they feel they are the failure in the marriage' (Janice, nurse, urology and neuro).

Conversely, there was also recognition that couples can become closer following a diagnosis of cancer, and that this can result in greater physical intimacy. This is exemplified by Jane's (psy, gynae) account:

I've found that some people have sort of had a renewed 'romance' in the relationship. I had one lady who ... her husband she said 'Oh, he used to be aloof but now he gives me kisses and we have dates', and her daughter comes to the group and she's like 'Oh my God, they're just kissing and cuddling all the time. It's revolting'. So it was really nice to hear. So some just have that spontaneous recovery and they do it themselves; there was nothing from me. They just 'this is important', they sort of had that near-death thing and gone 'Right ...' and they're seizing the moment sort of thing.

Jane was not positioning relational closeness as resulting from her intervention as a support group leader, but rather, as resulting from the reprioritisation that can take place

in the face of impending mortality (Ussher, Wong, & Perz, 2011). Other participants positioned improved intimacy as resulting from sexual renegotiation that was encouraged by health professionals. As Andrea (psy, gynae) told us ‘I think for some of them that take on board that it’s not all about penetration, can get a different sort of sex life that’s more satisfying in some ways’.

Subject positions adopted by health professionals in relation to sexual Communication

‘Sex should be part of the agenda with patients’: positioning sex as an essential aspect of health professional communication and patient support

The corollary of acknowledging the existence of changes to sexual well-being post-cancer was that discussion of sexuality was positioned as central to cancer care. As Maria (psy, general) commented:

We need to speak and discuss sexuality and intimacy because often there’s a lot there but they don’t feel that they can communicate it with anyone else, and sometimes we’re the first people to ask about it as well and it can be a major contributing factor to people’s well being.

The function of this discussion was deemed to provide information and alleviate distress about the impact of cancer on the sexual body. Thus, Andrea (psy, urology) said that it was important to discuss erectile functioning with men who had prostate cancer ‘just to make sure that it is okay and that it may still be an issue for them if they can’t get erections anymore’. Michele (sw, haem) reported that ‘one of the bigger things is dispelling all the mythology around not being able to have sex’, either because of misconceptions that cancer was contagious, or that sex would damage the person with cancer. Education about the effects of cancer on sexual functioning or desire was positioned as central to dispelling sexual myths and concerns: ‘I think even if you can’t do something about it, one of the important things is to reassure people that there’s no physical problem’ (Gail, Dr, general).

Education about supportive interventions that may alleviate sexual concerns was also described as essential. Ruth (Dr, gynae) said that it was important to educate women who had undergone vaginal surgery about the use of dilators, which serve to ‘keep the vagina open so that when and if you do have sex then it’s more comfortable because you haven’t got a narrow, fibrotic vagina’. Even if women did not have penetrative vaginal sex, dilators could serve to make ‘pelvic examinations more comfortable’. Basic education about sexual anatomy was also identified as helpful, ‘getting out diagrams to actually go through the anatomy of what happens down there and what comes and goes into what and out of what, and how it all works’ (Patricia, nurse, gynae). Educating people with cancer and their partners about alternative sexual practices when coital sex was no longer possible was positioned as of central importance. As Maree (psy, general) told us, people need help in ‘thinking of some other ways that you’ve got to be sexual’ such as ‘encouragement to gently touch themselves or touch each other’. Permission to engage in non-coital intimacy could also be given:

I guess a part of that is just giving people permission to be able to, it's okay if they don't have, if they don't have penetrating sex, intercourse, but they can be comforting and loving and close and all of those things. (Peggy, sw, general)

In a number of accounts, participants focused on the sexual information needs of specific groups of individuals. For example, men with cancer were identified as needing information about non-coital sex: 'I think intimacy means more than sex, I think people need a lot of education around that especially men I think can really sort of fall into that trap' (Megan, psy, general). Others focused on the importance of 'normalising discussion of sex' for younger people:

I think a lot of it is about supporting young people through normal adolescent development. So all the normal stuff around sexuality and life choices and things like that before they're even diagnosed with cancer and the complications impact as a result of that. (Lisa, nurse, general)

Younger patients were also described as needing information about fertility: 'So right from the start, there needs to be this brief discussion of "your fertility may be affected"' (Mark, Dr, haem). The sexual needs of partners were also identified in a number of accounts: 'it's important that health care professionals discuss the effect of cancer on the sexual relationship with partners of people with cancer' (Angela, nurse, general); 'partners of patients, who don't have an understanding of what cancer is, might feel like they might catch a disease' (Stacey, Dr, gynae).

In combination, the accounts presented in these three themes suggest that the health professionals interviewed in the present study constructed sexual changes post-cancer in physical, psychological and relational terms, and positioned such changes as having the potential to significantly impact on patient and partner well-being. This was associated with widespread adoption of a discourse of psychosocial support, which legitimated discussion of such changes within a clinical consultation, in order to alleviate distress, dispel myths and facilitate renegotiation of sexual practices. However, this did not necessarily translate into practice, with the majority of participants identifying personal, patient-centred and situational factors as barriers to the discussion of sex within many clinical consultations.

What do health professionals position as barriers to sexual communication in the context of cancer?

Almost all of the participants positioned sexuality as a difficult subject to discuss, because it is a 'no go zone', a 'private thing', a 'personal thing to bring up', a 'can of worms' or a 'sensitive issue'. In some instances, this positioning encouraged the health professional to be 'proactive' in 'putting the issue on the table' (Angela, nurse, general), as a result of awareness that others may not be doing so. For example, Cathy (psy, general) said: 'I make the effort to do that because I know that for whatever reason it may not have been addressed previously, there may be a gap'. However, in a significant proportion of accounts, the difficult nature of the subject matter served as an explanation for why sex was *not* broached in a clinical consultation. In accounting for their unwillingness to address sexuality, health professionals identified a range of barriers, which

are outlined in the three discursive themes below: knowledge, confidence and comfort; positioning sex as irrelevant or inappropriate for some people; context and prioritisation.

'We really are not as equipped as we'd like to be': positioning knowledge, confidence and comfort as barriers to discussion of sexuality after cancer

I feel that we haven't put enough priority around it. And it's something that's, sort of swept under the carpet and if the clients bring it up that's okay, we address it but we really are not as equipped as we'd like to be. (Olive, sw, gynae)

Absence of education and training was positioned as the primary explanation for why sexuality was not discussed in a clinical consultation, even when sexual changes were acknowledged to be important. For example, in the account above, Olive positions health professionals as not having 'put enough priority' around discussion of sex, because 'we are really not as equipped as we'd like to be'. The consequence is that many of the health professionals see themselves as doing 'more listening than instructing', because they do not feel 'trained or experienced enough to be able to provide factual information or sex therapy for people' (Nancy, sw, general). Lack of training or expertise was also the explanation for why only 'simple stuff' or 'basic stuff' was covered when sex was discussed, with onward referrals made if the issues were more complex: 'I don't get into any nitty-gritty details, but simple stuff, for example, fearful it's going to hurt, I'll deal with that' (Nigel, Dr, gynae).

At the same time, many of those who gave accounts of discussing sexuality on a regular basis in consultations described having built up expertise through education or experience. For example, Lisa (nurse, general) said that 'I used to work in palliative care and I think we do a lot of education and work around it (sex) in palliative care', which served to 'equip us with those skills and normalise it'. Penny (nurse, breast) described herself as having 'grown in confidence in talking about it (sex) over the years' despite having been 'initially uncomfortable':

But it's been a lot of hard work and if I had been able to have some sort of educational guidance on how to talk to the people about things, how to initiate the discussions and such, it would have made life a lot easier.

Conversely, personal discomfort or lack of confidence was positioned as central to the reluctance to discuss sexuality with cancer patients, even when knowledge was present. For example, Maree (psy, general) described psychologists as 'normally able to pretty much talk about most things (laughter)', but reluctant to broach the subject of sex because 'it's more a confidence thing'. Maria (psy, general) said that 'I would speculate that people feel out of their depth with it, yeah and I do too. Like there's times when I go, "oh I don't know how to deal with this"'. Reluctance to discuss sexuality was also attributed to health professional discomfort, embarrassment and 'hang ups'. For example, Leanne (sw, haem) told us 'it's an area that generally I feel that uncomfortable talking about', and Marion (Dr, general) described a young couple who she saw every few weeks, and where she felt 'sure it's an issue', but 'I don't feel comfortable bringing

it up yet'. Discomfort was also associated with absence of rapport or connection with a patient, indicating the intersubjective nature of clinical interactions:

If I'm with someone who I haven't connected with very well or if it's a bit stilted and I feel I haven't made the connection, and I don't think they're feeling comfortable with me and I'm not feeling comfortable with them, I think that would make it very hard. (Andrea, psy, urology)

In each of the above accounts, participants acknowledge their own discomfort or lack of confidence. However, the majority of participants positioned others as uncomfortable or embarrassed: 'it's possible that health professionals are to blame for that because you know it's about them being comfortable enough *themselves*' (Peggy, sw, general); 'so *they'll* mention it because they have to but sort of are quite embarrassed themselves to talk about it' (Debra, nurse, colorectal); 'doctors are probably worried to bring it up, because *they're* worried about what the patient will think, and as a consequence, it ends up being not discussed' (Mark, Dr, haem). Each of these participants used the pronoun 'they' to distance themselves from avoidance of discussion of sex, which was positioning as common practice for others. This serves to normalise any discomfort experienced, as well as obviate scrutiny of the practice of the individual participant.

Many participants stated that health professionals should raise the issue, as patients may be 'embarrassed', and will 'want to discuss it but they won't bring it up' (Lisa, nurse, general). However, *other* health professionals were positioned as the most appropriate person to raise the issue of sexuality in a number of accounts, which again served to absolve the participant's own profession, and themselves, from responsibility for such discussions. For example, Colleen (nurse, general) stated that doctors were responsible: 'I think a lot of it should come from the doctors because they have a much more ongoing and intimate relationship with the patient'. Mark (Dr, haem), argued that clinical psychologists should raise the issue: 'I think it probably is part of the role of the clinical psychologist who's looking at psychological issues, of dealing with the cancer, to bring issues of sexuality up'. In contrast, participants who reported that they always raise the issue of sexuality with their patients positioned it as a concern for *all* health professionals, illustrated in Maree's account, below:

Putting it on the agenda for all health professionals is really important, because I think otherwise people assume that it's the counsellor's business or the social worker's business or the nurse's business or someone else, and then we don't talk about it.

This example acknowledges the potential consequence of discursively positioning the discussion of sexuality as the responsibility of others – it may not be discussed by anyone.

In each of these accounts, participants are positioning themselves, or other health professionals, as naïve, as inexperienced, lacking in confidence and uncomfortable when discussing sex with clients. The adoption of such a subject position functions to silence sexual communication, because good professional practice involves practicing within one's area of knowledge and expertise. Addressing sexuality could also serve to undermine the authority of the health professional, who is expected to exhibit knowledge,

confidence and skill in order to maintain their legitimacy in the health sphere (Jones & Porter, 2002).

'There are certain groups that it's much easier to talk about sex with': positioning sex as irrelevant or inappropriate for some people

In many accounts, patient attributes and assumptions about patient needs were proffered as explanations for why sexuality was not discussed during certain consultations. Patients who were of older age, had a non-reproductive cancer, and were not in an intimate relationship, were most commonly positioned as asexual or disinterested in sex, functioning to make sexual discussions with such patients irrelevant or inappropriate. Drawing on broader cultural discourse which positions older people outside of the boundaries of sexuality (Gott & Hinchliff, 2003), older patients were described as not 'worrying about sexual contact so much', 'over the sex' (Debra, nurse, colorectal) and 'not as sexually active (as) a young group of people' (Jennifer, sw, general). This functioned to position sex as 'unimportant, less important' for such individuals (Megan, psy, general). Difficulty experienced by the health professional in raising the subject of sex with an older patient was also described as a contributory factor. For example, Maria (psy, general), who was in her early 30s, commented: 'a lot of people that we do see are 50s/60s/70s/80s and it's hard to talk about that, so it's a generational thing as well'. Michelle (sw, haem) focused specifically on the difficulties of talking to older men: 'I think it's quite difficult to talk about those things with older men and I can't even remember a time where I have in all honesty'. When older patients made it clear that they were sexually active, the response was often surprise, as Renee (psy, gynae) said:

with quite elderly patients, I'm always surprised at how many say to me 'Oh yeah, well we are reasonably sexually active' ... you know, even people in their 70's and you think 'Oh, gosh' you know – 'don't shoot myself in the foot and say something stupid'.

Relationship status was also reported to contribute to health professional reluctance to discuss sexuality, with patients who were single being excluded from such discussions. This is illustrated in the following accounts: 'I'd feel like I couldn't bring it up with someone who didn't have a significant other' (Michele, sw, haem); 'I guess it doesn't come up as much and that might be that we don't probe as much because of their relationship status' (Maria, psy, general). Individuals who had non-reproductive cancers, or who were in the palliative stages of cancer, were also positioned as outside the boundaries of sexuality, as evidenced in the following examples: 'it's not something I go out to ask everyone about routinely unless they are specifically a gynae or a prostate patient' (Gail, Dr, general); 'they're in hospital. So obviously they're not going to be having sex, they're desperately ill' (Leanne, sw, haem).

At the same time, other patient attributes, including gender, sexuality and cultural background, were positioned as factors that potentially made discussion of sexuality difficult. For example, men were described as taking 'a long time to open up and tell you if they have got any problems' (Angela, nurse, general), meaning that 'it's much harder to go there' (Megan, psy, general). Conversely, a number of male health professionals reported that 'female patients are less likely to want to raise it with males' (Stephen, Dr, gynae), and that 'it'd be a bit hard for a younger lady to come up and especially to

a male in a nursing role' (Paul, nurse, haem). There was also concern about male health professionals raising the subject of sexuality with women patients, as they could be 'viewed in a different light' if they did so, and their intentions misconstrued, which meant that they were on 'safer ground not making a big issue of it' (Stephen). Individuals from 'non-English speaking backgrounds' were described as not wanting to 'have that sort of discussion, or perhaps don't feel that it's so appropriate' (Cathy, psy, general), with 'cultural influences' and 'religious beliefs' meaning 'you can't just go barging into it, it does have to be a considered approach' (Olivia, sw, gynae). Knowing whether a patient was gay or lesbian, and tailoring information accordingly, was also construed as difficult, as sexuality was not always disclosed 'because they're not sure how we're going to react' (Patricia, nurse, gynae). Only a minority of the participants expressed confidence in discussing gay and lesbian sexuality. For example, Cathy (psy, general) said she always discusses sexuality with same sex couples, because she is aware it is 'more likely not to have been raised with them, compared to other people'.

The position being adopted in each of these accounts is that it is either unnecessary, or inappropriate, to discuss sexuality with specific groups of patients, and that if sexuality was broached as a topic for discussion, this could be met with a negative reaction. This is illustrated in the account below, describing raising the subject of sexuality with people who have a 'totally unrelated cancer': 'a lot of people, I think, would be quite offended and quite shocked, intimidated and like, you've gone beyond this boundary, it's not your job, butt out' (Gail, Dr, general). This construction of sexual communication as 'not your job', and of patients as asexual, or likely to be 'offended' and 'intimidated', further serves to legitimate health professionals avoiding the subject of sexuality. It also exonerates them from any criticism that they should be raising it in consultations, as they position themselves as a sensitive health professional simply acting in the best interests of the patient. These accounts stand in contrast to those of health professionals who reported that they always raise sexuality, regardless of culture, age, gender or relationship status:

I suppose when it comes to raising sexuality issues what we normally say is our number one rule is to assume nothing, so we ask everybody no matter what their age, their cultural background, their relationship status because from time to time we have had people raise questions that we might not otherwise have predicted. (Maria, psy, general)

Equally, the positioning of particular groups of patients as 'difficult' to talk to was contested in a number of accounts: 'there is no difference speaking to a man of seventy about his sexual performance, desires, whatever, as there is in speaking to a twenty-five year old with testicular cancer' (Janice, nurse, urology & neuro); 'we have a huge diversity of ethnicities and religions ... but I have this strong belief that all these women have a right to have the information' (Patricia, nurse, gynae). This suggests that the positioning of sex as inappropriate or irrelevant for certain groups of patients is not inevitable, if health professionals accept discussion of sexuality as part of their professional role.

'Time constraints and the lack of privacy': limitations of the clinical context

The context of the clinical encounter was positioned as contributing to the absence of discussion of sexuality in many accounts. This included the absence of time, lack

of privacy, presence of others and the prioritisation of issues other than sex. The issue of limited consultation time was predominantly associated with medical general practitioners and oncologists, whose ability to discuss sex during a consultation will depend on 'how many patients they've got to see in a short period of time' (Stacey, Dr, gynae), as broaching the subject of sex will 'definitely double your consultation time' (Gail, Dr, general). This was reported to result in the sentiment: 'oh look I'm the oncologist, I've got fifteen minutes I'm not going to talk about your sex life with you' (Marion, Dr, general). This was positioned as appropriate, as 'it's not the sort of thing you can give an off the cuff remark and then leave it for later' (Annie, Dr, breast), as life and death issues were prioritised in time-limited consultations:

Sexuality gets pushed into the background because in oncology you tend to have a run of tragic cases and the sexuality side of things just gets pushed to the background in those patients because you're just struggling to keep them alive. (Andrew, Dr, gynae)

Lack of time could also make it difficult to develop rapport with a patient, which was positioned as central to feeling comfortable: 'it takes time to build that rapport before I'd be comfortable to go towards that subject' (Lauren, nurse, breast).

The invisibility of sexuality on routine clinical checklists was also a contributory factor to keeping sex 'off the radar': 'there are forms they fill in about their bowel movements and [laughs] how much they are eating, but there's no reference on forms and things about how their sexual relationship is going' (Lorraine, nurse, leukaemia). Avoidance of sexuality issues served to reinforce the silencing of sex, as experience was never developed: 'because you never open the lid you don't have the skills to do it in that short period of time' (Marion, Dr, general). Absence of privacy in a clinical consultation was also positioned as an inhibiting factor. For example, Paul (nurse, haem) said he often had 'more than a couple of new patient talks going on at once', which meant that it was not appropriate 'to bring up your sex talk in a room full of nine other people peering down at them'. Others discussed the absence of privacy on communal wards, where consultations often took place:

I think one of the problems on the wards too, is the fact that the curtains are very thin. And I think that if someone, a medical student rocked up to a patient and asked them about their sexual function and it was a four-bedded room and there were three other people sitting up and the room went quiet, you'll know damn well they're listening for the answer. (Gail, Dr, general)

The presence of a partner, family member or friend was also reported to limit privacy and curtail discussion. Many participants said that 'it's not appropriate when the partner is there' (Gail, Dr, general). Others said that patients 'come in with their children and their own parents, and you have to be careful about that' (Stacey, Dr, gynae); or, 'if I'm seeing an elderly woman and she's got a daughter or a son with her I won't discuss sex in front of the son or daughter but will do it at another opportunity' (Patricia, nurse, gynae).

The absence of services for onward referral was also considered to justify avoidance of the 'can of worms' that a discussion of sexuality could open up. For example, Lauren (nurse, breast) said that 'we don't have psychology services readily available for patients to offer additional counselling', and Nancy (sw, general) said that 'but I really

don't know if there's anything in (place) that would provide a support for people with chronic illness as well as their sexual relationship'. This absence of services was identified as particularly acute in rural areas, with Nigel (Dr, gynae) saying that 'the problem is that the infrastructure's not there for country patients' and Penny (nurse, breast) commenting that 'services out in the rural area are much reduced compared to the metro area'.

In each of these accounts, explanation for the absence of discussion of sex is positioned as outside of the control of the individual health professional, which leads to a position of helplessness, and absolves from responsibility those who avoid such discussion. Instead, critical attention is given to the structure of health systems, including lack of privacy and absence of referral sources, or to the practicalities of the clinical encounter, in terms of time limited consultations and presence of others. In both cases, the individual health professional is implicitly positioned as respecting the needs of the patient in avoiding discussion of a 'sensitive' subject when conditions are not ideal for doing so. Whilst these material constraints do exist, there were also accounts where such constraints were overcome, through participants making time, creating privacy, sourcing onward referral or adopting practical strategies:

There's a good brochure on sex after treatment for prostate cancer. I will give them that and then talk about it at the next session, saying 'have you read that brochure, what do you think'? (Andrea, psy, urology)

In the inpatient setting, because privacy can be an issue, often I will try and go back a second time and see if I can catch them either alone, or just with their partner, and if possible do it then. (Cathy, psy, general)

These accounts reflect the adoption of a discourse of agency and responsibility, where material context is positioned as something to be overcome, rather than a barrier to communication.

Discussion

Confirming previous research findings (Haboubi & Lincoln, 2003; Lindau et al., 2011; Stead et al., 2003), the health professionals interviewed in this study acknowledged the existence of sexual changes following cancer, and positioned sexuality as an issue that was important for patients and their partners. In contrast to previous qualitative research conducted in the Australian context (Hordern & Street, 2007a), where acknowledgement of sexual changes focused on erectile functioning, menopause, contraception and fertility, participants in the present study described a wide range of sexual changes, physical, psychological and relational. This may reflect the increased attention given to sexuality within oncology in the decade since Hordern and Street's study was conducted, evidenced in sexual practice guidelines, conference papers and research publications. However, constructions of sex as a physical act, defined within a coital imperative, where sex = vagina/penis intercourse (McPhillips, Braun, & Gavey, 2001) were predominant, in both descriptions of sexual changes, and in accounts of barriers to communication. This reflects the dominance of heterocentric biomedical discourse in research publications and practice guidelines associated with cancer and sexuality (Hordern & Street, 2007b; Hyde,

2007), and serves to marginalise the sexual needs and concerns of individuals whose cancer or cancer treatment does not directly affect the reproductive organs. It also reinforces the positioning of sex within narrow coitally focused constructions of sexual 'functioning' and performance (Traa et al., 2012), negating the myriad of ways in which individuals can renegotiate sex and intimacy in the context of cancer (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013), and marginalises those who are in non-heterosexual relationships (Brown & Tracy, 2008; Filiault, Drummond, & Smith, 2008).

Evidence of heterocentric biomedical constructions acting in such a matter were present in the positioning of sex as irrelevant or inappropriate for some people, those who were described as 'older', who did not have reproductive cancers, who were not in a relationship, or were in the later stages of cancer. It was also evident in accounts of difficulties in addressing sexuality with gay and lesbian patients. Whilst sexual functioning does decline with age and illness, there is consistent evidence that many older adults are sexually active (DeLamater & Sill, 2005; Lindau et al., 2007), and that sex remains an important aspect of well-being in later life (Gott & Hinchliff, 2003). Equally, there is growing evidence to suggest that sexual changes are experienced by individuals with non-reproductive cancers (Carolan, Meneses, Shell, & Zhang, 2008; Ramirez et al., 2010; Traa et al., 2012) and their partners (Hawkins et al., 2009). Sexuality is also a concern for many single people with cancer (Ussher, Perz, & Gilbert, 2012), those in palliative care (Hordern & Currow, 2003; Woodhouse & Baldwin, 2008), and those who are gay, lesbian or transgender (Brown & Tracy, 2008; Filiault et al., 2008). This suggests that constructions of particular groups of patients as asexual, or as unaffected by sexual changes, reflect cultural discourse associated with age, terminal illness and with sex as coital performance (see Hyde, 2007; McPhillips et al., 2001; Watters & Boyd, 2009; Williams, 1998), rather than clinical knowledge and experience. As a significant proportion of individuals with cancer do not have reproductive cancers, can be positioned as 'older', and are single, in the later stages of the disease, or in non-heterosexual relationships, the adoption of such a discourse serves to absolve health professionals from responsibility for addressing the 'difficult' or 'sensitive' subject of sexuality with a significant number of their patients. Silence about sexuality may also reflect a broader cultural discourse that sex is a 'private' subject, and that knowledge comes from personal experience of sexual relationships, leading to embarrassment on the part of clinicians (Meerabeau, 1999). This is borne out by previous research, which reported that health professionals acknowledge the importance of sexual issues in the context of cancer, but rarely discuss it in clinical practice (Haboubi & Lincoln, 2003; Hautamaki et al., 2007; Stead et al., 2003).

In the present study, the majority of participants also positioned sexuality as an issue that was important to discuss with patients, with the clinician having primary responsibility for raising this discussion. There was also widespread acknowledgement of the need for education and interventions to alleviate sexual concerns, with many participants adopting a psychosocial discourse in conceptualising such support. However, there was a disjuncture between discourse and practice, with the majority of participants describing multiple barriers precluding discussion of sexuality with patients including self-positioning as being uncomfortable, unskilled or lacking in confidence, sex as irrelevant or inappropriate for some patients, or structural constraints in the clinical setting, confirming previous research (Hordern & Street, 2007a, 2007b). This suggests that it is not absence of knowledge of the nature or importance of sexual changes following

cancer that act as a barrier to discussion, but a range of personal, patient-centred and structural factors, and the subject positions health professionals adopt in relation to each.

Lack of knowledge, confidence or comfort on the part of health professionals in discussing sexuality with cancer patients has been reported in previous research (Haboubi & Lincoln, 2003; Hautamaki et al., 2007; Lindau et al., 2011; Stead et al., 2003). This has led to the development of brief training programmes (Hordern et al., 2009), and publication of practical strategies to facilitate health professional communication about sex in the context of cancer (Hordern & Currow, 2003; Hughes, 2000; Katz, 2005; National Centre for Gynaecological Cancers, 2011). However, the success of such strategies depends on health professionals being reflexive in their practice, acknowledging their own limitations and accepting the necessity of professional training or development. If health professionals position lack of knowledge or training as limitations of *other* practitioners, as was the case with many participants in the present study, or adhere to discursive constructions of barriers as patient centred or contextual, such professional development is unlikely to be adopted. These barriers are not immutable, however, as is evidenced by accounts of participants in the present study who positioned themselves as knowledgeable and confident in discussing sexuality with patients, regardless of patient attributes, or clinical context. These participants adopted a subject position of agency and confidence in relation to communication of sexuality and intimacy in the context of cancer, rather than a position of naivety and inexperience. If health professionals working in cancer care were to adopt this agentic subject position, and conceptualise sexuality as a routine part of communication to elicit patient concerns (see Maguire & Pitceathly, 2002), they are more likely to feel empowered to address the sexual needs of their patients.

The findings of this study suggest that interventions to improve health professional communication need to focus on a range of material, discursive and intrapsychic strategies. The materiality of the clinical context, in terms of consultation time, privacy, inclusion of sexuality on clinical checklists and provision of onward referral sources, needs to be improved, in order to facilitate communication about sexuality, and provide support for health professionals when sexual difficulties or concerns require expert intervention. Clinical management teams also need to acknowledge the importance of sexuality, and support the utilisation of sexual communication skills (Maguire & Pitceathly, 2002), facilitating health professionals adopting an agentic subject position. Clear designation of responsibility for discussion of sexuality needs to take place within a clinical team, and awareness raised about gender and age differences between patients and clinicians which may complicate such discussions. Whilst there was no notable difference in accounts across those working with specific cancer types, participants from a nursing, social work or psychology background were more likely to report discussing sexuality with patients. This could reflect the greater time available in patient consultations, prior training or their adoption of responsibility for sexuality within a clinical team. However, as medical staff are more likely to interact with patients on an ongoing basis, and many patients and their partners do not ever interact with allied health professionals, it is essential that medical professionals are also trained, and develop confidence, in discussing sexuality in the context of cancer.

Specific training in discussing sexuality as part of basic communication training and ongoing professional development can address such concerns, and provide skills in

discussing sex in an appropriate manner (Maguire & Pitceathly, 2002); such programmes can also increase confidence, challenge sexual myths and increase the likelihood of sexual communication in a clinical context (Hordern et al., 2009; Rosen, Kountz, Post-Zwicker, Leiblum, & Wiegel, 2006). Details of specific strategies that can be adopted in raising sexual issues in a clinical context are now widely available (Brandenburg & Bitzer, 2009; Hordern & Currow, 2003; Hughes, 2000; Katz, 2005); these need to be utilised as part of normal clinical practice, with both patients and their partners, in order that health professionals develop the experience which facilitates confidence.

Discursive constructions of particular groups of patients as asexual or disinterested in sex need to be challenged, in order to undermine the discursive strategies that exonerate health professionals from discussing sex outside of the boundaries that they position as the norm. In this vein, there is a need for health professionals to be aware of the complex nature of changes to sexuality and intimacy after cancer, and importance of such changes for patients and their partners, regardless of gender, age, cultural group, sexual orientation or cancer stage and type. There is also a need for awareness that health professionals bear the responsibility for raising this issue with their patients, as many patients are too embarrassed to raise it themselves, or are concerned that it is inappropriate (Hordern & Street, 2007a). At the same time, information and checklists provided to people with cancer can facilitate their raising the subject of sexuality with clinicians, which can alleviate concerns that such discussion is unwanted (e.g. BCNA, 2011; Cancer and Sexuality Team, 2011). In conclusion, sex does not have to be positioned as a 'difficult' subject post-cancer; it can be conceptualised as a central component of quality of life and relationships, as it is at any time in life.

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