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Sexuality and Intimacy in the Context of Cancer

J. M. Ussher, J. Perz, E. Gilbert,
Y. Hawkins and W. K. T. Wong
*University of Western Sydney,
Australia*

1. Introduction

1.1 The impact of cancer on sexuality and intimacy: A key aspect of quality of life

In 2006, more than 106,000 new cases of cancer were diagnosed in Australia, with the number of new cases in New South Wales alone expected to grow to 40,116 by 2011 (AIHW et al., 2007, Tracey et al., 2005). It is now widely recognised that cancer and its treatment can have a significant effect on the quality of life of both people with cancer (Stommel et al., 2004) and their family members, in particular their intimate partner (Hodges et al., 2005). Sexuality and intimacy are important aspects of an individual's quality of life (World Health Organisation, 1995), and there is a growing body of evidence to show that cancer can result in dramatic changes to sexuality, sexual functioning, relationships, and sense of self, regardless of cancer type. Indeed, these changes can be experienced as the most significant in the person with cancer's life (Anderson et al., 2000).

For women, treatments for gynaecological, colorectal, or breast cancer can alter patterns of fertility, have a negative impact on arousal and orgasm, reduce vaginal lubrication and elasticity (Jvaskova et al., 2003), precipitate negative changes to body image and sense of self, or precipitate 'sexual dysfunction' (Maughan et al., 2002, Sundquist, 2002, Baider et al., 2000). For men, prostate and testicular cancer can impact on fertility, ejaculatory capacity, and erectile potential (Gurevich et al., 2004), as well as provoking diminished confidence, fear, and embarrassment associated with sexual ability (Bokhour et al., 2001). The fatigue caused by cancer and certain treatments, such as chemotherapy and radiotherapy, is also typically associated with diminished desire (Rolland, 1994).

Changes to sexuality post-cancer have ramifications beyond sex as an activity. It has been argued that when sexual intercourse ceases after illness, touching and other forms of affectionate physical contact also diminish (Kuyper et al., 1998), because of a perception amongst some couples that these forms of affection necessarily lead to sexual intercourse, which is either not possible, or deemed inappropriate (Hughes, 2000). Equally, if all forms of sexual intimacy within the couple relationship disappear, couples facing cancer can feel isolated, anxious, depressed (Germino et al., 1995), inadequate (Anllo, 2000), or emotionally distant from their partner (Rolland, 1994). Conversely, sexual intimacy has also been found to make the experience of cancer more manageable and assist in the recovery process (Schultz et al., 2003), or be central to couple closeness and quality of life in palliative care (Lemieux et al., 2004).

1.2 The experience of cancer on partners' sexuality

Whilst the experiences of partners are often neglected in research on sexuality and intimacy post-cancer (Reichers, 2004), there is growing acknowledgement of their unmet needs in this area (De Groot et al., 2005, Perez et al., 2002, Soothill et al., 2003). Reported disruptions, include decreases in their own sex drive; fear of initiating sex with their partner; difficulty regaining a level of 'normality' within the sexual relationship; and feeling unwanted and unattractive because of cessation of sex (Maughan et al., 2002, Harden et al., 2002, Sanders et al., 2006).

Whilst the inclusion of partners in research on sexuality and cancer goes some way to addressing the issue of 'carer blindness' (Parker, 1990), one of the limitations of existing research in this area is the focus on cancers that affect sexual organs, primarily prostate, breast and gynaecological cancer. There is a need for research examining the experiences of partners across a range of cancer types, as cancers that do not involve parts of the body designated as 'sexual' may also impact on sexuality (Reichers, 2004). Equally, the focus of research to date has been on the physiological effects of cancer and its treatment upon the sexuality of partners. However, sexuality is a material-discursive phenomenon (Ussher, 1997a), and thus the dynamics of the care-giving relationship, and social constructions surrounding what constitutes 'appropriate' or 'taboo' sexual conduct post-cancer, may also interfere with a couples' sexual relationship. Partners who provide a great deal of intimate physical care to the person with cancer (such as helping with toileting or feeding) can experience difficulties in continuing to see them as a sexual person (Pope, 1999), repositioning them as a 'patient' (Kelly, 1992) or as asexual (D'Ardenne, 2004).

Broader cultural constructions of normative sexuality may also be influential in determining the ability of couples to renegotiate sexuality and intimacy post-cancer, particularly when sexual intercourse is no longer possible. As Judith Butler (1993) has argued, our understanding of sexual subjectivity is confined within a 'heterosexual matrix', within which masculinity and femininity are performed through engagement in normative sexual practices, described as the "coital imperative" (Gavey et al., 1999), with failure to perform coitus positioned as 'dysfunction', and other practices as not "real sex" (Few, 1997). This provides a theoretical framework for understanding why many heterosexual couples who cannot physiologically engage in sexual intercourse following diagnosis and treatment of cancer cease all expression of sexual intimacy. It also suggests that the dynamics and pressures of the caring role, as well as constructions and beliefs about what is acceptable or appropriate sexually post-cancer, are worthy of investigation across cancer types. This is one of the aims of the present chapter.

1.3 Pathways to difficulty or re-negotiation of sexuality post-cancer

Much of the existing research in this area simply documents changes in sexuality and intimacy post-cancer, however, there have been some attempts to examine pathways to difficulty or re-negotiation, primarily within a uni-linear model, with each study focusing on one specific construct. Qualitative research has reported associations between cessation of sexuality and intimacy post-cancer and difficulties in couple communication about sexual matters (Arrington, 2003, Foy et al., 2001, Holmberg et al., 2001), often for fear of creating feelings of guilt in the person with cancer (Kuyper et al., 1998), and one quantitative study reported an association between communication, relationship satisfaction, and sexuality (Hannah et al., 1992). Equally, interviews with partners of a person with cancer, recently

conducted by the authors, revealed that successful re-negotiation of intimacy post-cancer was associated with good communication and positive relationship context (Gilbert et al., 2010a).

Until recently, research examining the impact of cancer on sexual wellbeing and intimacy has focused on the physical changes (Wilmoth, 2001), using quantitative methods of data collection – primarily surveys. Whilst quantitative methods can provide information on changes in large samples of individuals, they negate the lived experience and negotiation of sexual wellbeing after cancer (Gilbert et al., 2010b). At the same time, research has focused narrowly on ability to engage in satisfying sexual activity, satisfaction with the frequency of that activity (Wilmoth, 2001, Hensen, 2002), and the level of their sexual ‘dysfunction’ post-cancer, where functional sexuality is narrowly conceptualised as penile/vaginal intercourse (Fobair et al., 2006). Recent research has shown, however, that engaging in sexual intercourse may not be the primary focus of sexual concern after a cancer diagnosis, and that engagement in sexual intercourse does not necessarily equate to sexual satisfaction (Wilmoth, 2001). Moreover, the primary focus on the physical effects of cancer or cancer treatment on sexual behaviour assumes that the experience of sexuality is limited to its corporeal dimensions, negating the influence of the social and relational construction of sexuality and illness (Meyerowitz et al., 1999), and the ways in which the meaning of sex is negotiated by individuals (Gilbert et al., 2010a).

1.4 Prevention and intervention for issues of sexuality and intimacy post-cancer

Recognition of sexual changes and their consequences, and of pathways to difficulty, is only the first step: We then need to use this knowledge to develop, and evaluate, programs of prevention and intervention to ameliorate difficulty and facilitate re-negotiation of sexuality post-cancer. Equally, whilst a range of psycho-social interventions have been developed for both people with cancer and their carers, few interventions include consideration of sexuality and intimacy, and even if they do, sexuality is positioned as merely one aspect of the cancer experience that couples need assistance with (e.g. Helgeson et al., 2006, Wardle et al., 2003). It has thus been argued that there is a need for psycho-education, which focuses specifically on the effects of cancer and its treatments on sexuality and intimacy (Rees et al., 1998). Since 2003, psychosocial guidelines for the care of people with cancer include recognition of the need for support in relation to changes in sexual functioning post-cancer (Initiative, 2003). However, these guidelines do not provide practical strategies for the application of such support in clinical practice, and sexuality is still rarely addressed by health professionals (Hordern et al., 2007b).

Equally, those psycho-educational interventions that do exist tend to focus on restoring sexual functioning, rather than on examining the quality of intimate physical contact, or renegotiation of sexual relationships through the development of alternative practices (Hordern et al., 2007b). Interventions also focus on ‘sexual’ cancers, such as prostate (Manne et al., 2004), or breast cancer (Manne et al., 2007, Marcus et al., 1998, Lethborg et al., 2003), with little offered to address the needs and concerns of couples living with other types of cancer, and no analysis of the relative efficacy of interventions across cancer types. This chapter will address this significant gap in the research literature, by outlining the issues that need to be considered in psycho-educational interventions which address issues of intimacy and sexuality with people with cancer and their partners.

2. Methods

2.1 Design

The study described in this chapter is part of a larger cross sectional project evaluating the needs and experiences of informal cancer carers in New South Wales, Australia. This chapter focuses on the experiences of a sub-set of carers who were caring for their partners. All participants completed standardised questionnaires measuring depression and anxiety, burden of care, as well as questions regarding changes in sexuality post-cancer. Participants who reported changes in sexuality after the diagnosis of cancer, completed open-ended questions describing the changes. From these participants, a sample was selected to take part in in-depth interviews to examine these issues in more detail.

2.1.1 Recruitment and participants

The larger study from which the participants were drawn was advertised via cancer and carer-specific newsletters, websites, and organisations, as well as through media releases, cancer support groups and cancer clinics across New South Wales. Family members, partners or friends of people with cancer, who self identified as providing care, and who volunteered to take part in the research, were asked to complete an online or postal questionnaire. A subset of the participants, who indicated willingness, were invited to take part in an in-depth interview. Ethical approval was granted from all relevant Committees including 10 Area Health Services across New South Wales, Australia, The Cancer Council New South Wales, and the University of Western Sydney. Three hundred and twenty nine carers participated in this larger study. This paper draws upon a sub-sample of 156 (55 men, 101 women) participants who were caring for their partners and responded to the question 'does their cancer impact on your sexual relationship?'. One hundred and twenty-two participants (43 men, 79 women), or 78% of this sub-sample reported that the onset of cancer had negatively impacted upon their sexuality and their sexual relationship and completed open-ended questions describing the changes. When we examined the type of cancers associated with changes to sexuality post-cancer, the rate was 90% for partners of men with prostate cancer, 71% for partners of women with gynaecological cancer, and 78% for partners of women with breast cancer. Overall, the percentage of partner carers of partners with 'non-sexual' cancers who reported an impact on the sexual relationship was 76%, and the percentage of those caring for partners with cancers involving 'sexual' sites was 84%. Forty-six percent of partner carers indicated a willingness to be interviewed about sexuality and 20 were selected on the basis of whether they had been involved in, or were currently involved in, a sexual or intimate relationship with the person for whom they care/d, and self-reported changes to sexuality since the diagnosis of their partner's cancer, stratified by gender, cancer stage and type.

Sample characteristics are presented in Table 1. Ninety-six percent of the participants reported being in a heterosexual relationship, with the remaining in a lesbian relationship, and 1 participant in a gay male relationship. Participant ages ranged from 28 to 79, with a mean age of 57 (SD = 10.73; skewness = -.47), with their partner ages (person with cancer) displaying a comparable profile ranging from 29 to 93, with a mean age of 59 (SD = 11.83; skewness = -.15). Colorectal/digestive, breast and haematological cancer types account for 44.2% of the reported cancer types, 35% indicating an advanced stage of cancer, and the average time since diagnosis was 3.49 years. Carer partners reported spending an average of 10 hours per day providing direct care. There were 26 bereaved participants (11 men, 15 women), with the time of partner's death ranging from 1 month to 4 years, who reported retrospectively on their experience of caring for their partner.

2.2 Quantitative methods and analyses

2.2.1 Measures

The Hospital Anxiety and Depression Scale (HADS) (Zigmond et al., 1983), was used to provide a brief measure of the presence of anxiety and depression. The HADS has very well established psychometric properties and is a reliable and valid instrument, with Cronbach alphas at .80 to .93 for the anxiety and .81 to .90 for the depression subscales (Herrmann, 1997, Janda et al., 2008). Higher scores indicate higher psychological disturbances.

The Caregiver Reaction Assessment Scale (CRA) (Nijboer, 1999) was used to examine caregiver burden. Subscales include: Disrupted Schedule, Financial Problems, Lack of Family Support, Health Problems, and Self-Esteem. As an assessment of both positive and negative reactions to care-giving by partners of patients with cancer, the CRA has been described as a reliable and valid instrument, with Cronbach alpha coefficients ranging from .62 to .83 for the separate subscales (Nijboer, 1999). A higher score indicates a stronger impact of the attribute.

Questions on sexuality were also developed for the study, in consultation with the study's steering advisory committee, which comprised of two carer representatives from an independent advocacy organisation (Cancer Voices New South Wales), professionals providing support services to cancer patients and their carers, an oncologist, and researchers working in the field of psycho-oncology, sexuality, health, and gender. Three dichotomous questions (no, yes), asked participants: if they were in a sexual relationship with the patient; have there been changes to the sexual relationship post-cancer; and if so, have issues about sexuality been discussed with a health care provider?

2.2.2 Statistical analyses

Cronbach alpha coefficients were calculated to assess the internal consistency of HADS and CRA subscales. Cronbach alpha values above .80 were considered estimates of good reliability, while scores above .60 were considered adequate. A multivariate logistic regression with backward selection was conducted to determine the relationship between CRA subscales and impact on the sexual relationship to test the research question of the impact of burden of care on changes to the sexual relationship post-cancer. Univariate linear regressions with impact on the sexual relationship as a predictor and HADS Anxiety and Depression subscales as outcome variables, were conducted to assess the association between changes to the sexual relationship and psychological well-being. This analysis excluded data from the 26 bereaved participants, given that the HADS measures psychological well-being over last 7 days. To examine the potential moderating influence of participant gender, age, hours of provided direct care, and cancer type (dichotomised as non-sexual or sexual type), a series of multiple regressions were conducted where interactions with these variables were examined in addition to the main effect of impact on the sexual relationship. Cancer stage was not examined, due to the small cell size in early stage cancer. Equations with continuous predictor variables were centred as suggested by Howell (2002). An alpha level of .05 was used for all analyses.

2.3 Qualitative methods and analysis

2.3.1 Measures

Two open-ended questionnaire items concerning changes in sexuality post-cancer were: please describe the changes to your sexual relationship; and, if your role as carer has made

any difference to your sexual relationship, please describe this difference. Participants who were interviewed were asked the same set of questions, with scope to elaborate on topics or issues as they arose.

A semi-structured interview, audio-recorded and conducted on a face-to-face or telephone basis, lasting approximately 1 hour, was used to examine in depth partners' experiences of sexuality post-cancer. The interview discussion focused on: changes to partners' intimate/sexual relationship; feelings about their intimate/sexual relationship; communication with the person with cancer about intimacy; and experiences with health care professionals. In accordance with established protocols in qualitative research, sampling was discontinued when information redundancy was reached, and no additional information was forthcoming (Miles et al., 1994).

2.3.2 Analysis of open-ended questions and interviews

All of the interviews were transcribed verbatim, and thematic analysis was used to analyse the data (Braun et al., 2006). After transcription, the interviews and open-ended questionnaire responses were independently read by two researchers, in order to ascertain the major themes, and to develop a coding frame. Following discussion between the researchers, and other members of the research team, the coding system was used to organise the data into conceptual categories which were based on participants' stories and responses. The research was, therefore, largely inductive, where the concepts and categories came from the data, rather than being deductive or informed by existing preconceptions about cancer caring and sexuality (Janesick, 1994). The interviews and responses were then coded thematically by two of the researchers, using consensus discussion, with a third researcher available to discuss any disagreements. NVivo software, a program which allows for qualitative data to be organised thematically, as well as across demographic, or other key variables, was used to organise the coded data. The coding frame focused on the following major themes: Nature of changes to sexuality (cessation; reduction; renegotiation); Reasons given for changes to sexuality (Impact of cancer or cancer treatment: caring role; repositioning of person with cancer as patient); and Feelings about such changes (positive and negative). Discussion and competing explanations between the two researchers during the coding process, as well as discussions with the broader team, allowed the coding frame to be refined (Barbour, 2001). Responses from the questionnaire were also tabulated and counted to identify frequency and patterning within and across groups, specifically gender and cancer type.

3. Results

3.1 Quantitative results

3.1.1 Reliability estimates

HADS Anxiety and Depression subscales displayed good reliability with Chronbach alpha scores $>.80$ (.87 and .81 respectively), while the CRA subscales 'Disrupted Schedule' (.77) and 'Lack of Family Support' (.67) had adequate internal consistency with scores $>.60$. Cronbach alpha scores for the remaining CRA subscales were $<.60$ ('Self Esteem' at .56; 'Financial Problems' at .44; and 'Health Problem' at -.17). Descriptive statistics for the HADS and CRA subscale scores are presented in Table 1.

Variable	N	Mean	S.D.	Range
Partner carer age	153	57	10.63	28 - 79
Person with cancer age	154	59	11.83	29 - 93
Hours of direct care per day	116	10.25	9.06	0 - 24
Years since diagnosis	153	3.48	4.36	2mths - 23yrs
CRA subscale scores:				
• Disrupted schedule	152	17.17	5.18	0 - 25
• Health problems	153	13.23	2.56	3 - 19
• Lack of family support	155	9.28	4.75	0 - 25
• Financial problems	152	8.30	3.26	0 - 15
• Self esteem	152	26.19	4.49	5 - 35
• HADS subscale scores:				
• Anxiety	126	10.79	4.40	1 - 20
• Depression	125	7.38	4.11	0 - 19
	N	%		
Sexual orientation:				
• Heterosexual	149	95.5		
• Lesbian / Gay	7	4.5		
Ethnicity:				
• White European / Aust	141	90.4		
• Asian	3	1.3		
• Not stated	12	7.7		
Cancer type:				
• Colorectal/Digestive	24	15.4		
• Breast	23	14.7		
• Haematological	22	14.1		
• Multiple Non-Sexual	15	9.6		
• Multiple Sexual	10	6.4		
• Prostrate	10	6.4		
• Other*	52	33.4		
Stage of disease:				
• No longer detectable	29	18.6		
• Early	10	6.4		
• Advanced	56	35		
• Not sure/applicable	61	39		

* "Other" includes: Respiratory, Gynaecological, Brain, Mesothelioma, Pancreatic and missing.

Table 1. Sample characteristics for partner carer and person with cancer

3.1.2 Predictors of changes to the sexual relationship

Table 2 summarises the odds ratios ($Exp(B)$) for CRA subscales as predictor variables in a model predicting changes to the sexual relationship post-cancer. The CRA subscale “Disrupted Schedule” was the single significant predictor of changes to the sexual relationship ($Exp(B) = 1.20, p = .002, CI = 1.05 - 1.22$), indicating that a person with a one-point increase in CRA “Disrupted Schedule” would be 1.2 times more likely to report that the sexual relationship had changed post-cancer. No other CRA subscales emerged as predictors of change to the sexual relationship post-cancer.

CRA Subscale	$Exp(B)$	Significance	95% CI
<i>Variables in the model</i>			
Disrupted Schedule	1.20	.002	1.05 – 1.22
<i>Variables not in the model</i>			
Health Problems	.02	.86	.85 – 1.22
Lack of Family Support	.07	.16	.97 – 1.19
Financial Problems	.03	.73	.88 – 1.20
Self Esteem	-.02	.64	.89 – 1.07
Constant	-.73	.26	

Note: Model significant at the level of 0.01; -2 log likelihood = 145.84; $X^2 = 10.21$.

Table 2. Multivariate logistic regression results for factors associated with a change in the sexual relationship post cancer ($N = 146$)

3.1.3 Impact of changes in the sexual relationship upon psychological well-being

Table 3 presents the results of univariate regression analyses conducted to examine the contribution of the predictor variable ‘changes to the sexual relationship post-cancer’ on participant’s HADS Anxiety and Depression scores. Changes to the sexual relationship was a significant predictor of HADS Anxiety scores ($t_{(124)} = 2.04, p = .04$) and HADS Depression scores ($t_{(124)} = 2.02, p = .04$) respectively. Multiple regressions testing the main effect of changes to the sexual relationship and interaction terms representing potential moderating variables were conducted separately for gender, age, hours of provided direct care, and cancer type. No significant interaction effects were found predicting either HADS Anxiety or HADS Depression scores.

	B	$SE\ B$	β
<i>HADS Anxiety Subscale</i>			
Change in the sexual relationship	1.82	.89	.18*
<i>HADS Depression Subscale</i>			
Change in the sexual relationship	1.68	.83	.18*

Note: For HADS Anxiety, $R^2 = .03$; For HADS Depression, $R^2 = .03$. * $p < .05$.

Table 3. Univariate regression results for change in the sexual relationship upon psychological wellbeing ($N = 124$)

3.2 Qualitative results

One hundred and twenty two partners, including 26 who were bereaved, elaborated on the changes to their sexual relationship they had experienced post-cancer, in open-ended responses. These responses concerned the status of the sexual relationship, perceived reasons for the changes, and partners' feelings about the changed relationship. Each theme is reported below, illustrated by extracts from the questionnaires and the interviews. Demographic information is provided for longer quotes stemming from the interviews. For readability, these specific details are not provided for every questionnaire and interview quote. Percentages cited refer to the open ended questionnaire responses, completed by 122 participants.

3.2.1 Status of current sexual relationship

Two major themes characterised accounts of the current status of the sexual relationship: cessation or decreased frequency of sex or intimacy; and re-negotiation of sex or intimacy.

Cessation or decreased frequency of sex and intimacy. Complete cessation of sex, decrease in the frequency of sex, or a reduction in the frequency or quality of intimacy and closeness, was reported by 59% of women and 79% of men. The complete 'end' of the sexual relationship was reported by some participants as a sudden event: "Our sex life disappeared overnight"; "Gone from fantastic sex life to none". For other participants, it was a gradual change: "Initially we found other ways to be intimate, however over time our sex life has ceased". The impact of both the cessation of sex, and the loss of intimacy, was evident in the following interview extract:

A big... big chunk of your life is lost, And I don't just mean the physical aspects of it... I mean that's... you can live with that or you can... or go without, but... the whole package is gone and I think that's hard that, you're a widow with somebody that's still around.

57 year old woman caring for 53 year old husband with brain cancer

Of the participants who reported decreased sexual frequency, rather than complete cessation, many positioned their sexual relationship in ways that indicated that they had previously enjoyed an active sex life: "We had a very strong physical relationship up until the cancer was discovered and after it, it just faded away"; "Very poor, we use to have sex 5 times a week, now maybe once in 3 or 4 months". Others simply described a change in frequency: "Virtually non-existent"; "This aspect of our marriage has nearly stopped". Many participants also reported decreased closeness and intimacy. Responses included: "...I couldn't cuddle like we used to" and, "Often feel frustrated that it doesn't happen like it used to - he is not as romantic either". Participants also shared these sentiments in the interviews, for example:

I don't know whether you just take this huge step back and you're not feeling that intimacy, because I think it comes from fear that you start to think well, maybe they won't be around, and if this is the way it's going to be then I should start preparing myself rather than being clingy and wanting to be in their space.

52 year old woman caring for 55 year old husband with prostate cancer

Renegotiation of sexual and non-sexual intimacy post-cancer. Renegotiation of their sexual relationship, in terms of non-coital sexual practices, or the development of non-sexual intimacy, was reported by 19% of women and 14% of men. Men (12%) were more likely than women (1%) to report having developed alternative sexual behaviours to those practiced

prior to the cancer. This consisted of changed sexual positions when attempting intercourse: "I am obviously more careful, having adjusted positions"; as well as the development of "workable alternatives to achieve partner satisfaction... within restrictions caused by the treatments", including oral sex, massage, masturbation, or the use of a vibrator.

Women (18%) were more likely than men (5%) to report that re-negotiation involved non-sexual intimacy, such as hugging and cuddling: "I'd put my legs up on his lap, and he'd put his arms around me, and I'd cuddle into him, and we'd watch TV".

The last week of my husband's life, he wanted to make love, but physically could not due to his illness. We talked this over as we always did and he knew that hugs, cuddles and closeness were far more important than the actual act of making love.

64 year old woman who cared for 64 year old husband with pancreatic cancer, bereaved

The importance of this closeness to the well-being of both the partner and the person with cancer was emphasized by many of the interviewees. In the excerpt below, one partner describes how important it was to maintain physical closeness with her husband, despite the significant physical barriers that could have served to restrict the expression of intimacy.

We deliberately had kept the double bed. And then, when he got sick, and they needed a more supportive bed, I brought my single bed in, and we got this special height, set at the same height, so that we was always next to me. ... I remember the morning he died, I remember cuddling him all night. (...) Just to have your... to have your arm around him was just so, so good.

59 year old woman who cared for 69 year old husband with mesothelioma, bereaved

3.2.2 Reasons for changes in sexual relationships

Many of the participants provided reasons for changes in their sexual relationship post-cancer. These were: the impact of cancer treatment; exhaustion resulting from the caring role; and the re-positioning of the person with cancer as a patient, rather than as a sexual partner.

Impact of cancer treatment. Participants referred to "cancer" and then specified the impact of cancer treatment as the major reason for changes to the sexual relationship. Within this theme, reports of physical barriers to sex were reported by 30% of men and 33% of women. For some, the physical barriers were directly related to the physical outcomes of cancer treatment on sexual functioning, for example: "Hormonal treatment has the effect of chemical castration, i.e. my husband has no sexual function"; "her poor body has been so cut and chemo has affected her so much that sex is not even possible"; "...non-existent due mainly to the chronic pain syndrome and a less than full confidence in colostomy bags!" For others, abstinence was due to overall bodily restrictions: "... He is physically unable to position himself for sex now".

In June an epidural catheter was inserted into my husband's chest and commenced on morphine 30 mgs three times a day. Not only was there no energy or inclination, because of the pain and reduced energy, there was now a 'physical barrier' to our relationship as well as all the side effects of morphine.

59 year old woman who cared for 56 year old husband with mesothelioma, bereaved

Many of the participants also described side effects of the treatment such as pain, fatigue, and exhaustion. Pain was described thus: "When he is unwell because of treatment I tend to be very careful in touching him in case it causes further pain/discomfort". Descriptions of fatigue being given as a reason for changes to the sexual relationship included: "As a result of treatment (chemotherapy) my wife is tired more of the time and her libido is reduced";

"He was just too exhausted". The impact of cancer treatment on the self-esteem and self-image of their partner was also identified as a reason for changes to the sexual relationship in a number of cases. For example, one partner commented that:

As her health declined she had very low self esteem caused by loss of hair and muscle tone. When I did have sex at the beginning she would accuse me of not treating her the same as I did in the past and get depressed.

61 year old man caring for 43 year old female partner with lung cancer, bereaved

Exhaustion resulting from the caring role. In citing reasons for changes to the sexual relationship, exhaustion resulting from the caring role was positioned as the cause by 16% of the women and 9% of the men. The responses included: "We don't really have any intimacy anymore for reasons including his health and my exhaustion"; "Exhaustion, brain still ticking about things to be organised"; "Even if he was still interested in the sexual side of our marriage I think I would have been too exhausted to have taken part". Participants also commented on revised prioritisation, centred on coping and survival, leaving no time for sex or intimacy.

...sexual relations of any sort were not an option as I had to be on the go all the time, looking after her. My sexual desires, needs or wants were not in my mind.

62 year old man who cared for 64 year old wife with liposarcoma, bereaved

Re-positioning of person with cancer as patient. For 28% of women and 47% of men caring for a partner with cancer, the caring role was reported to have resulted in a re-positioning of the person with cancer as a patient, which subsequently influenced their sexual relationship. Many partners described emotional effects of the caring role, or concern for their partner's feelings and health status. Comments included: "With all the worry and stress that my husband is most likely to die, I now have very little desire for sex"; "Curbed by concerns about inflicting pain or discomfort";

I just wanted to treat her the same as I always did but I couldn't get the thought out of my head that she was terminally ill.

61 year old man caring for 43 year old female partner with lung cancer, bereaved

Participants also reported a redefined role or status as carer rather than lover. Examples included: "My role as a carer has overridden my role as a wife..."; "Having to spend more time on house/garden chores and be carer/nurse, one feels more like a housekeeper than a lover".

When you are a carer it's hard to be a lover, for either party, when dealing with incontinence of both bowel and bladder infections, along with the daily grind of showering, dressing, shaving, etc, then transferring from bed to wheelchair and return.

59 year old woman who cared for 63 year old male partner with haematological cancer, bereaved

A number of male participants gave accounts which suggested sex was 'inappropriate' with a person with cancer: "I was very aware of my role as carer and never did anything to embarrass my wife. There was never any inappropriate behaviour". This could result in ambivalent feelings in the face of the partners' own desires.

I feel disgusted with myself that I would inflict sex upon a dying woman, having said that my wife does not object and occasionally welcomes it, saying it is a life giving and loving act and a part of our sacrament.... I was never a fast lover, but now I try and get it over and done with for her.

45 year old man caring for 44 year old wife with breast cancer

In the interviews, a number of the women participants also described now positioning their partner as a child, which was antithetical to sexuality:

it's like looking after ...one of your children now. That's the feelings that you have, you know, you don't have any ..sexual feelings for your children ... (so) I just don't have them anymore.

57 year old woman, caring for 53 year old husband with advanced brain cancer.

3.2.3 Partners' feelings about their changed sexual relationship

In the open-ended questions, a number of the participants made comments about the emotions they experienced in response to these changes in their sexual relationship post-cancer. These were evenly divided between positive and negative responses.

Positive responses. Positive accounts were provided by 17% of women and 16% of men. Within this theme, participants described feelings of understanding or acceptance of the effects of cancer or caring on their sexual relationship.

Treatment makes my partner feel sick and makes me worry about him so this means we don't feel up to sex... This is not an issue – just a fact/reality of current situation.

39 year old woman caring for 53 year old male partner with lung cancer

A number of participants also reported affection and companionate devotion:

Sexual urge had gone but my husband made me feel the most loved and cared for woman on this earth by his loving actions, his consideration, his caring attitude and the advice I sought even up till 12 hours before he died. I loved this man totally and he me.

68 year old woman who cared for 69 year old husband with brain cancer, bereaved

In the interviews, a number of participants reported that the cancer experience had actually brought them closer together, with one man saying he “probably has a more affectionate relationship at this point in our lives, and marriage” than prior to the onset of cancer, and another commenting “with the exclusion of sex, our intimacy is closer probably than it's been for a long time”. A third male participant said that whilst he and his wife “haven't had sex (intercourse) as frequently”, he feels that his relationship is “better”, he feels “happier”, and feels as if he is a “more attentive partner” and a “better father”. Increased emotional closeness, despite absence of sex, was also evident in a number of the women participants' interviews:

We are so much closer now than we were....we wouldn't be as close now and we wouldn't be able to talk about absolutely anything now...Just seeing him at night, just makes my heart just go hshshsh.... Whereas before I don't think we appreciated that about each other.

29 year old woman caring for 33 year old husband with brain cancer

Negative responses. Negative feelings were reported by 13% of the women and 21% of the men who said that there had been a change in their sexual relationship. These responses included self-blame, “No sex for 12 months – more my fault”, and rejection by their partners “I felt excluded and unwanted. Sex became a chore and mechanical”; “She has absolutely no sexual interest in me whatsoever”. A number of woman participants also expressed rejection toward their partners:

I don't feel the desire to have a physical relationship with my husband. It almost makes me feel ill to even contemplate it. His whole physical appearance repels me.

52 year old woman caring for 55 year old husband with prostate cancer

Participants also reported lack of fulfilment in relation to sex: “Not able to relax and enjoy”; “Often feel frustrated that it doesn't happen like it used to”; “At times, I have considered having an affair purely for sexual gratification”.

...leaves me less satisfied – there was a time shortly a few weeks after she was diagnosed with breast-bone cancer where I found it hard to orgasm/ejaculate – I would fail twice after some minutes, then succeed the next day.

45 year old man caring for 44 year old wife with breast cancer

Some participants mentioned feelings of perceived obligation. For men, it was usually in relation to feeling that their partner felt obliged to provide sex. Examples included: “On the infrequent occasions we now have sex she wants it over and done with as quickly as possible”; “She became less interested in sex and only accommodated me as if it was a wifey duty”. For women participants, obligation was positioned in terms of themselves feeling obliged to engage in sex.

At the early stages of the diagnosis I felt that I couldn’t say no to him which put a lot of pressure on me. I had to make sure that I could respond to him and not give him any chance of feeling that I didn’t want to make love to him.

59 year old woman caring for 63 year old husband with gastric adenocarcinoma

A small number of women participants shared negative feelings regarding family planning and fertility:

Prostate cancer has required removal of the sac that produces sperm. I am 36 and had always taken for granted I would fall pregnant in the most natural and intimate way. Once my partner is stronger, we will seek advice from an IVF Clinic regarding artificial insemination (hence my partner has secured enough in the sperm bank!). Still this whole traumatic experience has left me feeling very upset.

36 year old woman caring for 59 year old husband with prostate cancer

Some participants reported feeling angry that their sexual relationship was ‘lost’, as one woman commented, “(I’m) so much crosser...because a big part of our relationship had just gone out the window”. Sadness at the loss of their sexual relationship was also evident in many of the accounts: “There is just an enormous sadness that we can no longer have this intimacy...”; “Still this whole traumatic experience has left me feeling very upset”; “it’s profound sadness, I mean very, very sad”, resulting in feeling “terribly fragile and vulnerable and sad, and so sorry that it was all going”.

3.2.4 Discussions of sexuality with health professionals

In response to a question regarding whether there had been discussion of sexuality with a health professional, 20% of partners indicated that there had. The rate of discussion differed across cancer types, ranging from 50% of prostate cancer partner carers, to 0% of respiratory cancer. The rates across the other main cancer types were: 33% brain; 33% pancreatic; 30% breast; 29% gynaecological; 20% multiple – sexual; 17% colorectal/digestive; 17% mesothelioma; 15% multiple – non sexual; 15% other; and 9% haematological. Of those who had discussed sexuality with health care providers, 30% stated that they were not at all or not very satisfied, 33% said that they were neither satisfied nor dissatisfied, and 37% indicated that they were satisfied or very satisfied.

In the interviews, a number of the partners commented on their discussions with health professionals, in each case giving a critical account. When they asked about sexual matters, partners reported being told “Oh you don’t need to know that and things like that”, or told that they were “irresponsible to be thinking about having children” in raising fertility as a concern. The majority, however, gave accounts of sexuality not being discussed at all: “I haven’t got a lot of medical advice about how we should continue to conduct our intimate relationship”; “they did not educate us on anything... at all”.

it's not properly addressed by the medical profession, it is just completely glossed over. And I can remember, you know, we were sitting when the diagnosis came through and the guy said well, you know, you'll get these hormone pills and we'll give you an injection into your stomach and of course that will be the end of your sex life; and we're just sitting there (...) That was the end of the discussion.

67 year old woman who cared for 85 year old husband with prostate, bowel, and lung cancer, bereaved.

4. Conclusion

This study examined changes to sexuality following the diagnosis and treatment of cancer, as well as the impact of such changes on psychological well-being, for informal carers who were the partner of a person with cancer. The mixed method design allowed for the extent and impact of changes to sexuality post-cancer to be measured using quantitative measures, and subjective experience of changes to sexuality to be evaluated using open-ended questionnaire items and interviews. Within a Critical Realist epistemological standpoint, each methodology is treated as equally valid in providing insight into the phenomenon under investigation.

The majority of participants reported that the cancer experience had impacted on their sexual relationship, resulting in a cessation or reduction of sexual activity, with only a minority renegotiating sexual intimacy post-cancer. This supports previous research which demonstrated that the impact of cancer and cancer treatment extends beyond the person with cancer (Baider et al., 2000, Gurevich et al., 2004, Juraskova et al., 2003, Maughan et al., 2002, Rolland, 1994, Walsh et al., 2005), reinforcing the need for acknowledgement of the sexual and intimate needs of partners, as well as of people with cancer. Rather than restricting our sample to partners caring for person with cancer affecting the reproductive areas of the body, we examined changes to sexuality post-cancer across a range of cancer types. The majority of participants who were providing support to a person with prostate, breast or gynaecological cancer cited an impact, confirming previous research (Maughan et al., 2002, Harden et al., 2002, Sanders et al., 2006). However the finding that a high proportion of partners of a person with 'non-sexual' cancer also reported changes highlights the pressing need to attend to and further investigate the sexual concerns and needs of all partners who care for a person with cancer.

The finding that partners who reported changes in sexuality post-cancer reported significantly higher levels of depression and anxiety than those who reported no sexual changes, adds support to the notion that sexuality is associated with cancer carers' quality of life and psychological well-being (Foy et al., 2001). Depression and anxiety may be a cause, or a consequence, of changes in sexuality post-cancer; further research is needed to examine this issue in more depth, looking at the factors which may moderate and mediate changes to the sexual relationship in cancer carers and their partners, as well as the consequences of such changes for the couple. Future research would also benefit from examining changes in sexuality and their impact across cancer stage, which was not possible in the present study due to the low numbers participants caring for someone with early stage cancer.

Whilst gender was not a significant moderator of impact of changes to sexuality on psychological well-being, there were some gender differences in the accounts of the nature of changes to the sexual relationship post-cancer. Reports of complete cessation of sex were more common for women than men, and very few women gave accounts of developing

alternative sexual practices if intercourse was no longer possible. This could be attributed to women being more likely to assume that they should subordinate their own needs to the needs of their partner (O'Grady, 2005), and to cultural constructions of normative heterosexuality which expect men to initiate sex (Ussher, 1997b). Previous research has found that partners are reluctant to initiate sexual intimacy if the person with cancer does not initiate (Maughan et al., 2002), and that heterosexual women partners do not wish to initiate sex, or discuss alternatives to coital sex, for fear of emasculating their partner if he can not 'perform' through sexual intercourse (Boehmer et al., 2001). This is consistent with research that has demonstrated that sexual performance is positioned as central to heterosexual constructions of 'manhood', with failure having negative consequences in terms of a man's sense of self (Tiefer, 1994).

Equally, the 'male sex drive discourse' which positions men as 'needing' sex (Hollway, 1989, Potts, 2002), may result in the sexual needs of male partners being classified by either or both members of the couple as being 'important enough' for sex to continue post-cancer, or for alternative sexual practices to be developed, in contrast to women partners who were more likely to report that re-negotiated intimacy was non-sexual. The phallogentric bias evident in the research and clinical literature on cancer and sexuality (Hyde, 2006), which serves to reinforce the notion that 'normal' sex = coitus, and emphasises sexual 'functioning' with little attention to alternative practices, needs to be challenged, as this potentially plays a significant role in the construction of truths about sexuality which people with cancer and their partners take up, limiting their exploration of alternatives to coitus post-cancer. However, in the present study, four of the six lesbian partners all reported complete cessation of sex, suggesting that even couples positioned outside of a heterosexual matrix (Butler, 1990) can experience changes to sexuality post-cancer.

Whilst previous research has attributed changes in sexuality and intimacy post-cancer to the physiological effects of cancer or cancer treatment, a finding confirmed by many of the accounts in the present study, our findings also showed that the caring role also had an impact on the sexual relationship (Hawkins et al., 2009). Participants who reported changes in sexuality post-cancer reported significantly higher scores on the disrupted schedule sub-scale of the Caregiver Reaction Assessment Scale, suggesting aspects of burden of care were associated with such changes. In the interviews and open ended questions, these participants also associated sexual changes with stress, fatigue and exhaustion, revised prioritisation centred on coping and survival, and a redefined status as carer rather than lover. Past research that has explored carers' experiences of stress and exhaustion primarily focuses on the impact upon carers' general health and well-being. For example, Brown and Stetz (1999, p. 186) found that the initial period of 'becoming a caregiver' is particularly stressful, as carers are focused not only on their new role, but also have to 'face the present', negotiate their choice/or lack thereof to care, develop competency around their caring tasks, and evaluate their future. It is important to further investigate how the stresses involved in being a caregiver impact upon a carer's sexuality, and how this may in turn impact on quality of life (Foy et al., 2001). The finding in the present study that women were more likely to report that exhaustion had an impact on sexuality is in line with previous research which found that women cancer carers experience greater personal costs from caring (Lutsky et al., 1994, Ussher et al., 2008). As these personal costs have been found to be associated with higher rates of depression and anxiety, as well as lower life satisfaction and quality of life ratings, (Hagedoorn et al., 2000, Bookwala et al., 2000), it is a serious health issue.

The impact of the re-positioning of the person with cancer as 'patient' or 'child', rather than as 'lover', is an important issue which requires further investigation. The finding that the physical symptoms of cancer, or the physical tasks associated with cancer caring, makes it difficult for many carers to continue to see their partner as a sexual person, confirms patterns found in other spheres of health care (Parker, 1990, Pope, 1999). This assignment of individuals with cancer with a 'sick' or 'childlike' identity, which is antithetical to an identity as a person with sexual desires and needs, can significantly impact on the sexual and intimate relationship of a couple facing cancer (Kelly et al., 1996). Sex can be positioned as 'inappropriate', or as a 'frivolous activity' (Holmberg et al., 2001), resulting in carers experiencing guilt in the face of their own sexual needs or desires, and the avoidance of any discussion or re-negotiation of sexual practices, as was reported in the present study. This could be seen as one aspect of a broader practice of self-silencing in cancer carers, where the needs of the carer are repressed, because the person with cancer has to be put first (Ussher et al., 2010). However, it is also associated with cultural discourses which position people with cancer as having limited sexual needs, or as asexual (D'Ardenne, 2004, Schildrick, 2005), resulting in a different set of norms being applied to what is acceptable behaviour (Wellard, 1998). The finding that male partners were more likely to report an impact of re-positioning the person with cancer as a patient may result from the role of carer being a more unfamiliar position for men to take up, given the congruence between femininity and the caring role (O'Grady, 2005). It may thus be more difficult for men to eroticize a partner with cancer who is in need of care. This matter is worthy of further investigation in future research.

As the majority of partners positioned these changes to their sexual relationship as problematic, confirming previous research (Kuyper et al., 1998, Perez et al., 2002, Reichers, 2004, Soothill et al., 2003, Thomas et al., 2002), this suggests that education and information about sexuality post-cancer which challenges myths and provides a framework for re-negotiation of sexual relationships, needs to be included in supportive interventions for partner carers. At present, there is a dearth of research in this area, with no published research examining cancer carer interventions with a sexual component (see Harding et al., 2003). The finding in the present study that some partners reported increased closeness and intimacy emphasises the importance of helping couples to re-negotiate intimacy and sexuality post-cancer, as well as the importance of recognising, and reinforcing, the rewards of cancer caring (Hudson et al., 2005, Sinding, 2003).

Whilst it has been recognised that health professionals need to discuss issues of sexuality and intimacy with patients in cancer and palliative care (Initiative, 2003), the findings of the present study confirm previous research which found that these discussions are not taking place for the majority of people with cancer or their partners (Stead et al., 2002), particularly for those outside the sphere of prostate cancer. Even when sexuality was discussed, this was not at a level which was satisfactory to the majority of participants in the present study. This confirms recent Australian research which reported mis-matched expectations and unmet needs in relation to communication about sexuality between health professionals and individuals with cancer (Hordern et al., 2007a, Hordern et al., 2007b), suggesting that further education and training of health professionals is required, in order that they will be able to advise couples affected by cancer on issues of sexuality and intimacy, and address their unmet needs in this arena (Rees et al., 1998). Without the legitimacy of being able to discuss potential or actual disruptions to the sexual relationship with a health care professional, partners may feel that they cannot discuss such issues with the person with cancer, and as a

result, may experience sadness, anger, and isolation (Gilbert et al., 2008), as was reported by many of the participants in the present study.

A number of methodological issues need to be considered when evaluating the findings of this research. Firstly, the issue of selection bias needs to be examined. The present study used self-selection in response to advertisement or information sheets distributed by cancer organisations or clinics, and thus may not have tapped a representative sample of informal cancer carers. Indeed, as noted above, future research in this field needs to systematically examine sexuality post-cancer across cancer stage. However, there was a good distribution across cancer type, gender and age-group, in contrast to many previous studies of cancer and sexuality which focussed solely on cancers affecting the sexual organs. Equally, as the participants were recruited for a general study on cancer caring, answering questions on sexuality as part of a broader questionnaire or interview, it could be argued that we have recruited individuals who would not usually respond to requests to take part in a research study on sexuality, and thus have obtained a broader sample for our research. Secondly, this study did not use standardised measures of sexual functioning, sexual or relationship satisfaction, but rather focussed on subjective reports through open ended questionnaire items or interview. Future research in this field could usefully adopt these standardised measures along side qualitative measures, to allow for greater triangulation of data, in evaluating of the extent and impact of changes to sexuality post-cancer. Thirdly, the cross sectional design meant that all assessment of change were retrospective. A longitudinal design would more effectively allow for the evaluation of changes to sexuality across cancer stage, and allow pre-post cancer treatment changes to be evaluated more thoroughly.

In conclusion, sexuality and intimacy are central aspects of quality of life that have often been neglected in examinations of the well-being of partners of a person with cancer. The findings of the present study add further support to the suggestion that sex should not be positioned as 'inappropriate' or 'trivial' in the context of cancer care, but rather be recognised as an aspect of couple relationships which is associated with well-being (Cort et al., 2004). Having health care professionals legitimate sexuality by 'giving permission' for couples to be sexually active or physically intimate when undergoing and recovering from treatment for cancer is one of the key strategies that could assist in this repositioning (Schwartz et al., 2002). The positive consequences of this may include increased feelings of well-being on the part of the partner carer, and closeness between the couple, which will have positive consequences for the physical and psychological well-being of the person with cancer (Hodges et al., 2005), the central aim of professional cancer care. There is thus no justification for sexuality and intimacy being ignored or dismissed: partner cancer carers are telling us that it is important, it is time for health professionals to recognise this need and to act accordingly.

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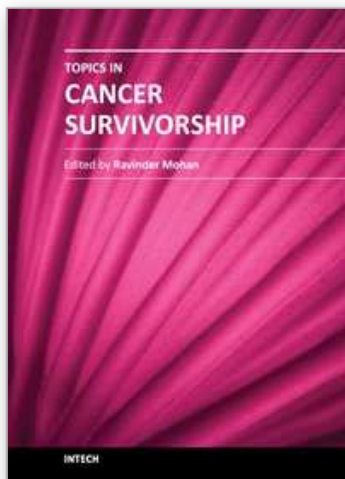
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Cancer is now the leading cause of death in the world. In the U.S., one in two men and one in three women will be diagnosed with a non-skin cancer in their lifetime. Cancer patients are living longer than ever before. For instance, when detected early, the five-year survival for breast cancer is 98%, and it is about 84% in patients with regional disease. However, the diagnosis and treatment of cancer is very distressing. Cancer patients frequently suffer from pain, disfigurement, depression, fatigue, physical dysfunctions, frequent visits to doctors and hospitals, multiple tests and procedures with the possibility of treatment complications, and the financial impact of the diagnosis on their life. This book presents a number of ways that can help cancer patients to look, feel and become healthier, take care of specific symptoms such as hair loss, arm swelling, and shortness of breath, and improve their intimacy, sexuality, and fertility.

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University Campus STeP Ri
Slavka Krautzeka 83/A
51000 Rijeka, Croatia
Phone: +385 (51) 770 447
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InTech China

Unit 405, Office Block, Hotel Equatorial Shanghai
No.65, Yan An Road (West), Shanghai, 200040, China
中国上海市延安西路65号上海国际贵都大饭店办公楼405单元
Phone: +86-21-62489820
Fax: +86-21-62489821

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