# Women's Experiences of Sexual Embodiment in the Context of Cancer

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Doctor of Philosophy

University of Western Sydney

2013

## Acknowledgements

This study was funded by an Australian Research Council Linkage

Grant, LP0883344, in conjunction with the Cancer Council New South Wales
and the National Breast Cancer Foundation, as part of a larger project entitled:
'Multiple perspectives on sexuality and intimacy post-cancer, leading to the
development and evaluations of supportive interventions'. I have appreciated
the opportunity to undertake this research.

I am grateful for the support of my supervisors over the course of conducting this study. Firstly, I would like to thank my primary supervisor, Associate Professor Janette Perz, for her support and guidance. In particular, her ability to navigate seemingly large and complex processes involved in research, making them achievable.

I am also grateful for the support and advice of Professor Jane Ussher, especially for guidance around my questioning of theories of subjectivity within critical psychology.

I would also like to say thank you to Dr Emilee Gilbert for her support and advice, particularly earlier in the process of my candidature and in posing some important questions in the process of setting up the study.

In addition, I have been grateful for other support I have received from within the University, especially the administrative assistance I received from Vicki Fox, and the encouragement I received from Dr Danuta Chessor.

I am thankful for the support of different friends and family over the course of this study. In particular, the support of my family, Benjamin,

Abigail, Tim, Keturah, and particularly my parents, Beverley and John. Thank you for your sureness and deep encouragement.

Thank you also to Eleanor, Michael, Helen, Sam, Sophia and Cat for their support and companionship at different points along this process. And, at the last few stages, thank you to Padraig and Lauren for their support and encouragement.

Finally, and significantly, thank you to the women who participated in this study and so openly shared their stories and experiences with me. I learnt much more than that which is contained in this thesis.

# **Statement of Authentication**

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

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Chloe Marie Parton

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#### Abstract

Cancer forms a significant health issue for women in Australia and globally, and can result in a range of embodied changes that affect women's experiences of sex and sexuality, continuing long after the conclusion of treatment. Cancer and cancer treatments can result in a range of bodily changes, including vaginal dryness, pain on intercourse, the loss of sexual desire, as well as disfigurement, scarring, bowel and bladder dysfunction, fatigue, and premature menopause. In addition, women report experiencing higher levels of depression and anxiety after cancer, as well as diminished body image and lowered feelings of attractiveness. Previous research has predominantly focused on the material and intrapsychic experiences of sexual changes after cancer, with discursive factors receiving less attention. However, women make sense of their subjectivities following cancer in relation to available discourses of cancer, heterosexuality and femininity. This suggests that research needs to pay attention to cultural discourse, as well as materiality and the intrapsychic. Further, there is a need to conduct research that privileges women's subjective embodied experiences as sources of knowledge, in order to examine how women experience embodied sexual subjectivity after cancer.

This study explored how women construct a sense of their bodies and sexual 'selves' in the context of cancer. In-depth semi-structured interviews were conducted with sixteen women across a range of ages, cancer types, and heterosexual relational contexts, including women who were, and were not, currently not in a long-term relationship. A material-discursive-intrapsychic

theoretical framework was employed, within a critical realist epistemology. A thematic discourse analysis was conducted drawing on feminist poststructuralist approaches to subjectivity, and the thematic organisation of interview material around subject positions.

Three overall themes were identified in the analysis: The Medical Body, The Abject Body and Positioning the Body Inside and Outside 'Sex'. In the theme 'The Medical Body', the women moved between positioning their bodies as 'object', without agency and distanced from discourses of femininity and sexuality, and as 'subject', taking up more agentic subject positions and beginning to re-embody 'sex' after cancer. In the theme 'The Abject Body', the women positioned their bodies beyond abnormality, outside discourses of idealised femininity, and out of control. Accounts of taking up the abject body were characterised by failure, self-blame and shame, while accounts of managing and resisting the abject body included concealment, resisting discourses of feminine beauty and positioning the body as the site of personal transformation. In the theme, 'Positioning the Body Inside and Outside 'Sex', the women positioned their subjectivity around hegemonic cultural constructions of hetero-sex. Accounts of the women positioning themselves inside 'sex' included experience of bodily ease during sex, or containing risk to sexual subjectivity by managing the body during sex. Accounts of the women positioning their subjectivity outside 'sex' included experiencing loss of sexual desire, vaginal dryness and pain on intercourse, or absence of sexual relationships.

Overall, in this analysis the corporeality of the cancerous body can be seen to disrupt hegemonic discourses of femininity and sexuality, with implications for how women practice and make meaning of their embodied sexual subjectivity. Implications of this research for theoretical, research, policy and clinical practice are examined, focusing on the need to create 'space' for women's bodies and embodied experiences after cancer.

# **Chapter One: Introduction**

This thesis will examine women's experiences of sexual embodiment in the context of cancer. Women's bodies and sexualities as they are subjectively experienced, and the ways that dominant discourses concerning femininity and heterosexuality shape the possibilities and limitations of embodied experience for women, are currently under-acknowledged in existing research on the psychological consequences of cancer. As well as contributing understanding to the ways that cancer can affect women's sexuality, this thesis also seeks to contribute further knowledge to literature that has examined the relationship women have with their own bodies and 'selves', and how these are produced within social contexts, including illness and intimate heterosexual relationships.

This introductory chapter will provide background to the study through contextual information about the prevalence of cancer for women in Australia and the influence cancer and cancer treatments can have on sexuality, body changes, and psychological distress. It will also consider cultural discourses around women's bodies, heterosexuality and femininity that are important to take into account within a study on women's experiences of sexual embodiment. The theoretical background to the study will be introduced, which together with the background information, informs the research aim and questions. Finally, the overall organisation of the thesis will be outlined.

#### Women and Cancer in Australia

Cancer is a disease that damages body tissue through the presence of defective cells that multiply out of control, with the potential to spread to other parts of the body (AIHW & AACR, 2012). It forms a significant health issue for women in Australia, as well as globally (Ferlay et al., 2010). Statistics of cancer prevalence in Australia in 2010 predict that one in four women in Australia will be diagnosed with cancer by the age of 75 and one in three by age 85, with rates of diagnosis increasing over time (AIHW & AACR, 2012). Further, cancer is currently the second leading cause of death in Australia and the leading cause of disease burden, formulated on the impact of premature death, disability and prolonged illness. The types of cancers experienced by women in Australia are variable, with the most commonly diagnosed cancers being breast, bowel, skin melanoma, lung and uterus (AIHW & AACR, 2012). Like other developed countries (Ferlay et al., 2010), the survival rates for cancer in Australia are continuing to improve over time (AIHW & AACR, 2012).

Common treatments for cancer include surgery, chemotherapy, radiation and hormonal treatments. Cancer and cancer treatments can result in a range of physical changes to the body, as well as ongoing uncertainty around cancer recurrence, existential threat (Hubbard & Forbat, 2012; Thomas-MacLean, 2005), and psychological distress (Grabsch et al., 2006; Härter et al., 2001; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). These consequences of cancer, along with changes to subjectivity that are associated with cancer (Kaiser, 2008; Little, Paul, Jordens, & Sayers, 2002;

Mathieson & Stam, 1995), have led cancer to be positioned as a chronic illness (Little, 2004). Further, improving survival rates mean that the number of women who are living in Australia having had a cancer diagnosis at some point in their lives is also continuing to increase (AIHW & AACR, 2012). This means that the number of women living with changes to their bodies, sexualities, sexual practices, psychological distress, and the chronicity of cancer, is also increasing.

Sexuality and sexual practices are important experiences to consider in constructions of subjectivity (Weeks, 2003), including how we position ourselves and bodies in relation to intimate others (Bryant & Schofield, 2007), as well as within our social worlds (Holland, Ramazanoglu, Sharpe, & Thomson, 1998). Further, changes in bodily practices of sex can shape the way we experience our sexuality, acting as transforming events in constructions of sexual subjectivity (Bryant & Schofield, 2007). Women's experiences of their bodies and sexual subjectivities are important to consider in the context of cancer, as studies suggest that sexual changes are common after cancer (Ganz et al., 2004; Jensen, 2007; Lange et al., 2009; Traa, De Vries, Roukema, & Den Oudsten, 2012), and can occur well into 'recovery' (Jensen et al., 2004).

Previous research has tended to address different aspects of women's sexuality through the sexual functioning of the body, 'body image' and feelings of sexual attractiveness, psychological distress, and the dynamics of heterosexual couple relationships (Gilbert, Ussher, & Perz, 2010b, 2011). When considering the impact of cancer on sexuality, many studies have

focused on the impact of cancer treatments on the ability of women to engage in coital sex (Hyde, 2007). These studies have found that coital sex can be disrupted due to vaginal dryness, pain on intercourse, vaginal shortening and narrowing, scarring of vaginal tissue, and changed physiological sexual responses that have an effect by diminishing sexual desire, arousal and impairment of orgasm (Aerts, Enzlin, Verhaeghe, Vergote, & Amant, 2009; Donovan et al., 2007; Hendren et al., 2005; Maas et al., 2004; Pieterse et al., 2006). In addition, coital sexual functioning has been found to be affected by 'indirect' effects of cancer on women's experiences of sexuality and femininity, including diminished body image (Donovan et al., 2007; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Green et al., 2000), lowered relationship quality (Holmberg, Scott, Alexy, & Fife, 2001) and psychological distress (Schmidt, Bestmann, Küchler, Longo, & Kremer, 2005; Stewart, Wong, Duff, Melancon, & Cheung, 2001). Further, there are a number of findings in the existing studies that suggest women have changed feelings and make lowered evaluations of their bodies following cancer, including lowered perception of body image (Avis, Crawford, & Manuel, 2004; Moreira et al., 2011), decreased feelings of sexual attractiveness and increased psychological distress (Beckjord & Compas, 2007; Reich, Lesur, & Perdrizet-Chevallier, 2008). Further, based on non-cancer studies, it is likely that these psychological consequences of cancer have 'indirect' affects on women's experiences of sex, by increasing monitoring of the body and lowering sexual desire (Tiggeman, 2011; Woertman & van Den Brink, 2012). These findings suggest that women are often dealing with changed bodies, which may affect

the way that they make sense and experience their bodies and sexualities after cancer.

Currently, the predominant focus of research that examines women's experiences of sexuality following cancer has been on the biomedical functioning of the body, and forms of 'psychosocial adjustment' to the physical and psychological affects of cancer. As such, there is a lack of integration of discursive factors as they contribute to women's experiences of sexuality (Gilbert et al., 2010b, 2011), including a lack of consideration of the construction of sexuality within heterosexual discourse (Hyde, 2007). Discursively informed studies have suggested that people with cancer have to negotiate liminal illness identities that are associated with chronicity (Little, Jordens, Paul, Montgomery, & Philipson, 1998; Manderson, 2005). For example, some common experiences of cancer, including body changes, uncertainty, loss of control of the body, risk and existential threat, produce conditions that people have to manage and make sense of in order to negotiate the suffering that is associated with these experiences, and make sense of their 'selves' within this context (Little et al., 2002; Mathieson & Stam, 1995; Thomas-MacLean, 2004b). Such negotiation of identity has been positioned as making sense of the relationships between "body, self, and society" (Williams, 1996, p. 32). Currently, few studies have examined the way the women experience their sexual embodiment within this context (Gilbert, Ussher, & Perz, 2013).

# Sexuality and Women's Embodied Subjectivity

Having outlined the background context to women's experiences of cancer in Australia, it important to consider the discursive contexts that women occupy when taking up sexual practices. Firstly, cultural discourses of femininity tend to be organised around their relationship to hegemonic constructions of 'sex' and sexual attractiveness, with idealised constructions of femininity occupying a dominant positioning within Western cultural contexts (Ussher, 1997a). Culturally desirable forms of femininity are those that are strongly linked to the male gaze (Berger, 1972), emphasising youth and beauty (Bordo, 2003). Meanwhile, cultural discourses around sex and older women tend to distance older women from sex, leading to such women being positioned as less sexually desirable (DeLamater & Sill, 2005; Watters & Boyd, 2009). Further, the tendency for women to be judged on the appearances of their bodies, results in cultural dynamics in which women become conscious of their bodies in everyday life (Fredrickson & Roberts, 1997), monitoring and regulating their bodies through practices that are designed to bring them closer to ideals of feminine beauty (Bordo, 2003). As such, embodied experiences of cancer, which produce a range of different body changes, including those that are disruptive to practices of 'sex', may have important implications for women's experiences of sexual subjectivity.

Sexual subjectivity is relational, formed through intersubjective embodied sexual practices, and mediated by the cultural discourses that shape the meanings and dynamics of these experiences (Bryant & Schofield, 2007). In addition, women in particular are judged according to their ability to take

up particular relational positions, including securing long-term heterosexual relationships (Reynolds, 2008; Ussher, 1997a), and privileging the needs of others over their own (Jack, 1991). Contributing to this context, heterosexuality is structured by 'normative' discourses of sexual practices, that have the effect of positioning body practices as 'normal' or not, and bodies as 'functional' or 'dysfunctional' (Tiefer, 2004), with sexual practices structured around 'real' coital sex, as opposed to 'alternative' or 'precursor' non-coital sexual practices (McPhillips, Braun, & Gavey, 2001). Further, dominant discursive constructions of heterosexual men as having a biological need for sex are likely to contribute to the shaping of cultural dynamics in intimate heterosexual relationship (Hollway, 1984). As such, it is important to consider how normative discourses of heterosexuality inform how women relate sexually (or not) to heterosexual male partners. And also, how heteronormativity informs women's feminine subjectivities in the context of present or possible future heterosexual relationships.

Discourses of femininity and sexuality have close links to discourses of individualism and health (Bordo, 2003; Chrisler, 2012). For example, sexually desirable forms of femininity are often positioned as exemplifying the embodiment of 'health', through discourses of control over the body in the production of sexually desirable feminine bodies (Bordo, 2003). Such discourses may be problematic for women who are measured against cultural standards of idealised femininity, with embodied control over the body standing as symbolic of control over wider life (Chrisler, 2008). Further, 'sex' is also often constructed as a 'natural' and 'healthy' aspect of adult life (Hyde,

Nee, Butler, & Drennan, 2011). Such discourses have the affect of confronting social taboo's that can exist around sexual practices, particularly in aspects of sexual experience and practice that fall short of cultural ideals of desirable and 'normal' sex. However, it is possible that discourses that associate the embodiment of sex with constructions of 'normality' and 'health' may inform the difficulties in sexual experiences of women who have problematic experiences of sex, or fall short of heterosexual norms. This is particularly so in the context of experiences of illness, treatment, and embodied changes that are uncertain and which may challenge the ability for women to exercise control over their bodies.

# Women's bodies, power and regulation.

Women's experiences of sexual embodiment in the context of cancer can also be positioned as part of a broader cultural context of the relationship women have with their bodies and 'selves'. As noted above, many of the structures of cultural meaning relating to femininity position women in relation to heterosexual men, and specifically, the male gaze (Ussher, 1997a). This dominant cultural gaze is often internalised by women (Foucault, 1975), and produced as part of 'individual' experience, subsequently contributing to experiences of self-blame and shame when women are unable to realise unattainable idealised cultural standards of femininity through the monitoring and regulation of the body (Bordo, 2003; Chrisler, 2008; Malson, 1998). As such, the meanings women make of their bodies and bodily experiences, including those of femininity and sexuality, occur in a cultural context through which women are defined by being culturally 'other' to men (Malson, 1998).

In this cultural context, women can become "alienated" from their bodies (Young, 2005, p. 80), perceiving their bodies through the internalised male gaze as 'object'. Further, these dynamics are evidence of the subjectification of women's bodies, viewed through a dominant cultural gaze that also have implications for women's experiences of 'self', including emotions, relationships, and morality (Jack, 1991; O'Grady, 2005).

A Foucauldian theorisation of power positions bodies as both the object of cultural discourses, as well as the site through which cultural power and meanings can be contested (Foucault, 1980). As part of recognising the fluid dynamics of power, bodily meaning and practices are able to enact agency in relation to hegemonic discourses (Foucault, 1984). Here, it is important to address women's experiences from a position of subjectivity (Brooks, 2007), privileging women's meaning making associated with their bodies and acknowledging the impact that dominant discourses have on shaping women's embodied experience, as well as observing opportunities for resistance (Gavey, 1989). This approach may allow sensitivity in understanding the complexity of women's experiences as they negotiate embodied experience as contested sites of meaning (e.g. Malson, 1998). As such, there is a need to examine how women experience and make meaning of embodied experiences of sexuality following cancer, while acknowledging the dominant heterosexual dynamics present in the cultural context that women's bodies occupy.

# **Focus of the Current Study**

The aim of the research presented in this thesis is to examine women's experiences of sexual embodiment in the context of cancer. The 'context of cancer' refers to any point in the cancer journey from diagnosis onwards, acknowledging the ongoing impact that cancer can have on women's lives (Kaiser, 2008; Little, 2004). This research aim is addressed through the following research questions: How do woman make sense of their body experiences and sexual 'selves' in the context of cancer? How do women understand and experience their sexual relationships in the context of cancer? A qualitative methodology was adopted for this study, in which semi-structured interviews were conducted with sixteen women across a range of types of cancer, ages, and heterosexual relationship contexts. The interview data was analysed using a thematic discourse analysis drawing on the theoretical approach outlined below, and discussed in further detail in Chapter Three.

## **Theoretical Approach**

The theoretical approach adopted in this study is a material-discursive-intrapsychic framework (Ussher, 2000), within a critical realist epistemology (Bhaskar, 2011). Formulated as collapsing the gap between constructionist and positivist approaches to knowledge (Parker, 1999), a critical realist epistemology acknowledges that there is a material world, but conceptualises our knowledge and experiences of this world as mediated through culture (Williams, 2003). This epistemology is compatible with a material-discursive-

intrapsychic theoretical framework, as it acknowledges the corporeality of women's bodies, as well as the importance of discursive cultural contexts in shaping the possibilities and limitations of experience, and women's intrapsychic negotiation of sexual changes (Ussher, 2000).

The material-discursive-intrapsychic framework adopted was informed by discursive poststructuralist theorisations of language, discourse, power, the body, and intrapsychic experience. Such approaches collapse the distinction often inherent in the production of psychological knowledge, by positioning subjectivity within the symbolic and discursive meanings produced in language (Henriques, Hollway, Urwin, Venn, & Walkerdine, 1984; Weedon, 1997). As such, we can be seen to inherit our cultural context with implications for how we construct and experience our embodied 'selves' (Malson, 1998). Further, poststructuralist approaches conceptualise gender and subjectivity as produced and performed through acts of subjectivity, including bodily practices (Butler, 1993). As such, the women in this study will be seen to be producing their subjectivities as 'feminine' and 'sexual' according to the particular cultural meanings that are adopted by the women and bodily practices that are described. Informed by psychoanalytic principles and concepts (e.g. Kristeva, 1982), such experiences and constructions are seen to have implications for women's intrapsychic experiences, including emotions and dynamics, such as repression, that may help women negotiate their experience.

# Use of terminology in the thesis.

There are problems identified with the use of the word 'dysfunction' in regards to women's sexual experiences, as it reflects a cultural bias based on the construction of heterosexual 'sex' as coital sex, and positions women's bodies as the site of individual pathology, and problematic if they cannot respond or perform to these cultural standards (Tiefer, 2004). Reflecting the positivist-realist epistemological position of the studies that are reviewed in the literature Chapter Two, I use the word 'dysfunction' to refer to study findings that focus on women's inability to engage in coital sex following material changes to the body following cancer. This is subsequently critiqued as part of an evaluation of biomedical and psychological research. I use the word 'dysfunction', partly italicised, to refer to the theoretical conceptualisation of bodies that are affected by chronic illness (Williams, 1996), which is discussed in Chapter Five. Further, I use the word 'functioning' throughout the thesis to refer to the materiality of the body, as changes to physiological processes and anatomical structures can affect women's experiences of sex, particularly coital sex.

In addition to this, I have used the word 'sex', in inverted commas, as part of acknowledging the social construction of heterosex as structured around the coital imperative (McPhillips et al., 2001), and in an attempt to problematise assumptions tied to practices and discourses of heterosex.

Further, I have also used the word 'sexuality' within the thesis to refer to broader and interrelated aspects of sexual experience including, 'self', the body, relationships and social contexts.

#### **Structure of the Thesis**

The thesis is organised in the following way. Chapter Two contains a review of previous research that has examined different aspects of women's experiences of sexuality after cancer. In order to capture aspects of women's sexual embodiment as they relate to the theoretical framework employed in this study, findings that relate to women's experiences of sexual outcomes, body image, psychological distress and relationship contexts will be critically reviewed. Further, this literature review examines the different aspects of sexuality covered in previous studies as they relate to the material, intrapsychic and discursive aspects of women's sexual experiences. Consistent with a critical realist epistemology (Bhaskar, 2011), the discursive section includes a critique of the cultural discourse that contributes to the production of knowledge in the area of cancer and sexuality, as well as findings of studies that have examined women's meaning making around body changes and experiences of cancer.

Chapter Three contains a review of poststructuralist theoretical literature as it relates to poststructuralist approaches to theorising women's embodied sexual subjectivity. This chapter examines how different 'strands' of poststructuralist theory, including those that draw on psychoanalytic theory, conceptualise 'the body' and 'embodiment', as well as 'subjectivity'. Literature is also reviewed which exemplify the application of these theoretical approaches to studies that have examined gendered and sexual experience. The different strands of theory discussed in the chapter place emphasis on material, discursive and intrapsychic aspects of experience. The

implications for theorising women's experiences of sexual embodiment are discussed.

Chapter Four reviews the methodological framework that is employed in the study. This includes the research design, procedures for contacting participants and conducting interviews, as well as methodological issues that were encountered. Further, the sample is also outlined, including an overview of the sample in the form of 'pen portraits' of the women who were interviewed to provide further context to the study and findings. A feminist poststructuralist informed thematic discourse analysis was conducted and the 'reflexive' and theoretically informed process of analysis of the interview material is discussed

Chapters Five, Six and Seven will present the findings of the analysis. Firstly, Chapter Five, 'The Medical Body' discusses findings as they relate to women's constructions of their sexual embodiment across the cancer chronic illness trajectory, including interactions with the medical system. Chapter Six, 'The Abject Body', discusses findings relating to the women's positioning of their bodies as 'abject' throughout their accounts, and the implications this had for the women making meaning of their sexual embodiment. And finally, Chapter Seven, 'Positioning the Body Inside and Outside 'Sex'', examines how the women position their bodies in relation to hetero-normative constructions of 'sex', with implications for the sexual practices of the women, as well as feminine and relational subjectivities.

The conclusion, Chapter Eight, reviews the research aims and methods, and discusses the overall findings of the study. Implications for women's experiences of sexual embodiment after cancer are discussed in terms of theoretical approaches to research, as well as research, policy and health service practice. Finally, limitations and recommendations for future research are discussed.

#### Chapter Two: Women, Cancer and Sexuality

A literature review of studies that have addressed sexuality as it relates to women following cancer was conducted. To cover the different aspects of women's sexuality currently considered, studies that examined sexual functioning, body image, sexual 'self-concept', psychological distress, and relationship dynamics, in the context of sexual changes following cancer, were included in the review. It was found that existing studies primarily focus on the sexual attractiveness of women's bodies and hetero-feminine sexual and relational practices. Cancer can disrupt the sexual desirability of the body, and the ability and willingness of women to engage in hetero-feminine sexual practices, facilitating the likelihood of psychological distress where disruption has occurred. Findings of the literature review are presented in this chapter, structured according to factors within the theoretical framework adopted, namely the material, intrapsychic and discursive aspects of sexual experience, to allow the contributions of these aspects of embodied sexual subjectivity to be examined (Ussher, 2000). There are limitations to structuring the review this way as many factors considered in the literature form multidirectional relationships across different themes within the theoretical framework. Furthermore, many factors can simultaneously form both indirect and direct pathways to sexual 'dysfunction' and other sexual outcomes following cancer. However, the interrelatedness and overlapping of different factors are characteristic of women's sexual experience (Koch & Mansfield, 2002; Tiefer, 2004), and were used to inform the approach to sexual embodiment adopted in this study. By adopting a material-discursive-intrapsychic theoretical

approach, the interconnectedness of different aspects of women's sexuality can be considered as grounded within subjective experience (Ussher, 2000).

The studies examined in this review were organised according to particular cancer types. Despite the range of possible cancer diagnoses, existing studies tend to focus on breast, gynaecological, and colorectal cancers. Breast cancer was most prevalent in the literature, followed by gynaecological cancers, and cancers of the colon and rectum. Fewer studies addressed sexual issues related to lung, anal, lymphomas and head and neck cancers. This chapter will firstly examine material aspects of sexuality considered in the literature including, corporeal body changes. Secondly, intrapsychic aspects of sexuality will be examined including psychological distress, body image, and the correlations between these factors and sexual outcomes. Further, individual factors including age, cognitive self-schemas and personality variables that influence sexual outcomes will be examined. The influence of heterosexual couple relationships on the psychological and sexual outcomes for both women with and without a partner will also be considered. Finally, discursive factors will be examined, including a critique of the studies examined, and a review of studies that have adopted a discursive approach to examining cancer, feminine and heterosexual subjectivities.

# The Materiality of Sexuality Following Cancer

This section reviews findings that examine the body changes produced by cancer and cancer treatments, and the relationship of these changes to sexual functioning. Often, more than one factor is present in sexual outcomes (Mercadante, Vitrano, & Catania, 2010), and it can be difficult to isolate particular 'causes and effect' relationships for sexual dysfunction. The material pathways to sexual dysfunction considered in the literature included the physiological impairment of sexual arousal, removal of reproductive organs, and compromise of the structural anatomy and tissue of the vagina and other reproductive organs. This section will outline the impact of common treatment modalities on sexual outcomes.

## The impact of cancer treatments on 'sexual functioning'.

# Surgery.

Surgical procedures upon the abdomen, pelvic region and genitals following cancer are associated with sexual dysfunction for women (Jensen, 2007; Traa et al., 2012). Studies in this area tend to focus on colorectal and gynaecological cancers, and, to a lesser extent, instances in which the ovaries are removed to prevent cancer recurrence, as can be the case in breast cancer. Sexual functioning can become impaired as a result of surgery through the removal of reproductive organs (Greenwald & McCorkle, 2008; Liavaag et al., 2008), trauma and scarring to non-cancerous tissue, structural changes, including the removal of tissue from the vagina or vulva (Aerts et al., 2009; Green et al., 2000), and damage to pelvic autonomic nerves involved in sexual arousal (Maas, Weijenborg, & ter Kuile, 2003; Schmidt et al., 2005). The presence of a greater number of vaginal changes has been associated with greater levels of sexual dysfunction (Donovan et al., 2007), as well as

psychological distress (Bergmark, Avall-Lundquist, Dickman, Henningsohn, & Steineck, 1999).

Surgical procedures for gynaecological cancers include hysterectomy and pelvic lymphadenectomy for cervical cancers, vulvectomy for vulvar cancers, hysterectomy and oophorectomy for endometrial cancers, and hysterectomy, oophorectomy and pelvic lymphadenectomy for ovarian cancers (see Jensen, 2007 for more detail). Radical hysterectomy has been associated with greater disruption of sexual arousal than total hysterectomy, which is likely due to nerve damage inhibiting vaginal blood flow and impeding arousal (Maas et al., 2004). Radical hysterectomy and pelvic lymphadenectomy are procedures that have been associated with an initial decrease in sexual activity post-surgery, a narrowed and shortened vagina, discomfort during sex due to a reduced vagina size, impaired arousal, decreased lubrication, dyspareunia, impaired orgasm, decreased sensation around the labia, and sexual dissatisfaction (Jensen et al., 2004; Pieterse et al., 2006; Serati et al., 2009). Furthermore, women who have received radical hysterectomy also report increased feelings of sexual uncertainty about the future (Hawighorst-Knapstein et al., 2004). Some of these problems continue into the long term with women reporting decreased sexual interest and a lack of vaginal lubrication up to two years following treatment, despite a significant proportion (91%) reporting the resumption of sexual activity at 12 months (Jensen et al., 2004). Conversely, a couple of studies found no significant changes in sexual functioning (Jongpipan & Charoenkwan, 2007), and an improvement of sexual functioning long term following a hysterectomy (Greenwald & McCorkle, 2008), particularly where pre-diagnosis symptoms that may have impaired sexual functioning are resolved through treatment. However, these differences have also been suggested to be due to methodological differences, including varied surgical techniques and the extent of tumour size (Gilbert et al., 2011; Jongpipan & Charoenkwan, 2007; Vrzackova, Weiss, & Cibula, 2010).

Oophorectomy, particularly in premenopausal women, has been associated with greater sexual dysfunction, decreased sexual pleasure and greater sexual discomfort (Liavaag et al., 2008). In combination with hysterectomy, oophorectomy has also been associated with lessened sexual enjoyment than hysterectomy without oophorectomy (Greenwald & McCorkle, 2008). Finally, in regard to gynaecological cancers, there is a current lack of studies addressing sexual concerns following vulva cancer (Jefferies & Clifford, 2011b). However, vulvectomy procedures are associated with significant sexual dysfunction (Green et al., 2000), scarring and disfigurement (Jensen, 2007) and loss of sexual enjoyment (Jefferies & Clifford, 2011a).

Sexual dysfunction has also been associated with surgical procedures for colorectal and anal cancers including high anterior, low anterior and abdominoperineal surgery (da Silva et al., 2008; Engel et al., 2003; Tekkis et al., 2009). Despite the use of nerve preserving techniques during surgery for colorectal and anal cancers, damage to autonomic nerves can occur, contributing to impaired sexual responses (Lange et al., 2009). Some studies suggest greater levels of sexual dysfunction are likely for those who receive

abdominoperineal surgery (Engel et al., 2003; Li & Rew, 2010; Vironen, Kairaluoma, Aalto, & Kellokumpu, 2006), and stomas (Engel et al., 2003; Traa et al., 2012). As such, colorectal surgery is associated with reduced levels of sexual activity (Lange et al., 2009), reduced sexual interest and desire, impaired arousal, decreased lubrication, altered orgasm, dyspareunia (Hendren et al., 2005), and increased sexual uncertainty about the future (Platell, Thompson, & Makin, 2004). Stoma surgery may be conducted where bowel functioning is temporarily or permanently impaired. Subsequently, women with stomas have reported decreased sexual desire and impaired orgasm (da Silva et al., 2008), dyspareunia and vaginal dryness (Lange et al., 2009).

#### Radiation treatment.

Studies tend to suggest that adjuvant pelvic radiation treatment is associated with greater sexual dysfunction and lower levels of sexual activity than surgery only (Birgisson, Påhlman, Gunnarsson, & Glimelius, 2007; Bruheim et al., 2010; Donovan et al., 2007; Frumovitz et al., 2005; Greimel, Winter, Kapp, & Haas, 2009; Jensen, 2007), although a couple of studies have reported findings to the contrary (Levin et al., 2010; Pieterse et al., 2006). Pelvic radiation can affect the mucosal layer of the vagina (Jensen, 2007), cause tissue damage and scarring, and damage pelvic autonomic nerves (Bruheim et al., 2010). As such, pelvic radiation treatment has been associated with greater sexual dysfunction (Lange et al., 2009), reduction in vaginal size, reduced vaginal elasticity, dyspareunia, lower levels of sexual interest (Donovan et al., 2007), difficulty with sexual arousal, impaired orgasm, decreased sexual satisfaction (Frumovitz et al., 2005), lower levels of sexual

activity (Greimel et al., 2009), and increased sexual uncertainty about the future (Hawighorst-Knapstein et al., 2004). Women who receive radiation also report more difficulty with menopausal symptoms, experiencing these as more disruptive and severe (Frumovitz et al., 2005).

## Chemotherapy and hormonal treatments.

Chemotherapy and hormonal treatments have been reported to affect reproductive and sexual functioning. Pre and peri-menopausal women who receive chemotherapy treatment are at risk of temporary or permanent ovarian failure and menopause (Rogers & Kristjanson, 2002). The likelihood of ovarian failure increases with older age, higher chemotherapy dosage, and longer duration of treatment. Chemically induced menopause is suggested to be responsible for a significant level of sexual dysfunction experienced by women following their cancer treatment. Women who receive chemotherapy as part of their treatment for breast cancer report lower levels of sexual functioning (Arora et al., 2001; Avis et al., 2004; Beckjord & Compas, 2007; Ganz et al., 2004; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998), with vaginal dryness and dyspareunia reported as the most significant sexual concerns (Ussher, Perz, & Gilbert, 2012).

Menopausal symptoms caused by temporary or permanent ovarian failure following chemotherapy treatment can continue while receiving hormonal treatments, such as tamoxifen, an estrogen receptor antagonist usually taken for five years following initial treatments (Glaus et al., 2006; Mourits et al., 2002). While some studies have found no effect on sexual

functioning for tamoxifen (Berglund, Nystedt, Bolund, Sjödén, & Rutquist, 2001; Ganz et al., 1998), other studies have found tamoxifen to be associated with vaginal dryness and dyspareunia, related to decreased sexual desire (Mourits et al., 2002). Further, menopausal symptoms have been identified across different types of hormonal treatment and have been more commonly reported by younger women, including hot flushes, weight gain and loss of sexual desire (Malinovszky et al., 2004). These symptoms tend to decrease after discontinuation of hormonal treatment, but are more likely to continue for women who have also received chemotherapy (Buijs, de Vries, Mourits, & Willemse, 2008; Mourits et al., 2002; Nystedt, Berglund, Bolund, Fornander, & Rutqvist, 2003).

# **Intrapsychic Experiences of Sexuality Following Cancer**

This section reviews findings that have examined the psychological consequences of cancer and the relationship of these experiences to sexual outcomes and wellbeing. The term 'wellbeing' is used in this section in relation to sexuality to account for the experience of intrapsychic states that contribute to sexual outcomes, beyond the corporeal functioning of the body that was described in the previous section. Intrapsychic factors were conceptualised in the studies as having risk and protective, as well as mediating and moderating effects on women's psychological experiences following cancer. These factors will be examined in this section in relation to cancer, psychological distress, and sexual functioning; as well as body image, psychological distress and sexual functioning. Further, in order to address a move towards more individual level variables in existing studies to account for

sexual change and distress, the review will also examine variables of age, cognitive structures, and personality that are considered to influence the relationships between body image, psychological distress and sexual outcomes in women with cancer. Following this, findings that examine the influence of heterosexual couple relationships on women's sexual functioning, psychological distress, body image and wellbeing will be considered. Findings that relate to sexual changes for women who are single will also be examined.

## Psychological distress and cancer.

A population based study of psychological distress in cancer patients in the United States, conducted across cancer types and gender, found the overall prevalence of psychological distress in cancer patients to be 35.1% (Zabora et al., 2001). Prevalence of psychological distress differed according to the cancer site, with the following findings reported: lung cancer (43.4%), breast cancer (32.8%), colon cancer (31.6%) and gynaecological cancers (29.6%). Further, women with cancer have been found to experience affective and anxiety disorders up to two times more frequently than that for the population of women without cancer (Grabsch et al., 2006; Härter et al., 2001; Reich et al., 2008), although this has also been disputed (Boyes, Girgis, Zucca, & Lecathelinais, 2009). Women who are diagnosed with advanced cancer (Andersen, 2009; Grabsch et al., 2006), and who have greater impaired physical functioning (Härter et al., 2001), also report higher levels of psychological distress. Longitudinal studies have suggested that psychological distress and psychological quality of life improve over time for cancer survivors (Burgess et al., 2005; Parker et al., 2007). However, a number of

studies have indicated that psychological distress is an ongoing concern for a proportion of women following cancer, many of whom have a previous history of depression or anxiety (Boyes et al., 2009; Burgess et al., 2005; Costanzo et al., 2007; Reich et al., 2008).

## Psychological distress and sexual functioning.

Psychological distress has been examined as a potential factor related to lowered sexual functioning and wellbeing after cancer. Women who report depressive symptoms are more at risk of sexual dysfunction (Green et al., 2000; Kissane et al., 1998; Levin et al., 2010; Reese & Shelby, 2011), lower sexual quality of life (Beckjord & Compas, 2007), and less sexual satisfaction following cancer (Webber et al., 2011). Further, women who report sexual dysfunction also report higher rates of psychological distress than women without sexual problems (Spencer et al., 1999). Conversely, women who report more positive psychological health are less likely to report sexual dysfunction, and report greater sexual satisfaction (Ganz et al., 1999; Ganz et al., 2004). These findings suggest a bi-directional relationship between psychological distress and sexual functioning where women experiencing anxiety and depression may be more likely to report sexual dysfunction (Bradford & Meston, 2006; Cyranowski, Frank, Cherry, Houck, & Kupfer, 2004), and the presence of a sexual dysfunction may be more likely to result in greater psychological distress (Laurent & Simons, 2009), particularly in cases where intimate relational dynamics are disrupted (Hammen, 2003; Stephenson & Meston, 2010).

The findings in these studies resonate with the findings in non-cancer studies that examined the relationship between psychological distress, sexual problems and sexual wellbeing in women, where sexual satisfaction does not tend to be predicted by symptoms of sexual dysfunction, but by psychological wellbeing and relational intimacy (Dennerstein, Guthrie, Hayes, DeRogatis, & Lehert, 2008; Dundon & Rellini, 2010). For example, one population based study conducted in the United States found that 40 per cent of women reported experiencing an issue relating to their sexual functioning (Shiften, Monz, Russo, Segreti, & Johannes, 2008). However, only twelve per cent of women reported experiencing distressing sexual problems. Women who reported symptoms of depression were also found to be more likely to report experiencing distressing sexual issues, and further to this, emotional closeness within couple relationships was found to mediate the relationship between sexual distress and symptoms of sexual dysfunction. Such findings indicate that it is important to consider the relational contexts of sexual activity for women when examining incidences of psychological distress relating to sexual functioning.

#### Body image as a psychological consequence of cancer treatments.

Body image was a common psychological consequence of cancer examined in the studies reviewed, and was often conceptualised as an evaluative outcome of different forms of treatment, particularly in the area of breast cancer. Breast cancer researchers have examined evaluations of body image as an outcome of surgery type, differentiating between breast conserving treatment (lumpectomy and radiation treatment), mastectomy

without reconstruction, and mastectomy with reconstruction. A number of studies have found that women who have had a mastectomy initially report higher levels of body dissatisfaction than those with breast conserving surgery following treatment (Arora et al., 2001; Avis et al., 2004; Härtl et al., 2003; Markopoulos et al., 2009; Moyer, 1997; Vos, Garssen, Visser, Duivenvoorden, & de Haes, 2004).

A systematic review comparing the psychosocial outcomes of breast-reconstruction surgery to mastectomy concluded that body image outcomes based on surgery type were similar (Lee, Sunu, & Pignone, 2009). While some studies reported more positive body image outcomes for breast reconstruction (Nicholson, Leinster, & Sassoon, 2007; Rubino, Figus, Lorettu, & Sechi, 2007), others reported no significant differences (Avis et al., 2004; Harcourt et al., 2003; Rowland et al., 2000; Yurek, Farrar, & Andersen, 2000). Three studies were evaluated by Lee et al. (2009) as higher quality due to the use of validated measures and large sample sizes in two studies (Janz et al., 2005; Rowland et al., 2000), and the use of a prospective design in a third (Arora et al., 2001). Based on the findings of these studies, Lee et al. (2009) concluded that women report poorer body image outcomes after cancer and that there is no conclusive difference for women receiving breast reconstructive surgery over mastectomy only.

In another study, a meta-analysis was conducted which compared body image outcomes for breast conserving surgery and breast reconstruction, and modified radical mastectomy and breast reconstruction (Fang, Shu, & Chang, 2013). Overall body image scores were calculated, constructed of the sub-

factors 'body concern', being one's satisfaction with physical appearance, and 'body stigma', being one's need to keep the body hidden. Participants receiving breast conserving surgery reported higher overall body image scores than participants receiving breast reconstruction, with similar levels of 'body concern' and more positive reports of 'body stigma'. Breast reconstruction participants reported higher overall body image scores than mastectomy, with more positive reports of 'body concern' and more negative reports of 'body stigma'. The authors concluded that breast reconstruction could assist in creating a physical appearance that appears 'normal' under clothing, but does not remove the psychological perception of having abnormal breasts. These findings are supported by those described in a qualitative study, which suggest that the experience of receiving a breast reconstruction is complex beyond the restoration of breast shape, and can be complicated by the absence of sensation, cold skin, and coming to terms with a new 'artificial' part of the body (Snell et al., 2010).

While body image has not been given the same attention in studies of gynaecological cancers as it has with breast cancer, a few studies included measures of body image, or qualitative descriptions of change to body image after gynaecological cancers. Women with cervical cancer have been found to report diminished body image after cervical cancer, particularly women who also had received radiation treatment (Hawighorst-Knapstein et al., 2004). In another study, women with vulva cancer also report significantly lowered body image (Green et al., 2000). These studies suggest that women with gynaecological cancers may experience lowered self-confidence and sexual

attractiveness, as mediated by measures employed by both studies that directly addressed these aspects of experience. Further, qualitative studies have suggested that experiences of changed body image after cancer are linked to femininity, including both the internal and external aspects of the body (Butler, Banfield, Sveinson, & Allen, 1998). As such, women with gynaecological cancers have been found to report lowered body image, which was linked to femininity and fertility in instances of internalised bodily change (Juraskova et al., 2003), as well as experiences of weight gain (Burns, Costello, Ryan-Woolley, & Davidson, 2007).

A few studies have specifically examined the impact of hair loss as a result of chemotherapy on body image concerns for ovarian (Sun et al., 2005), gynaecological (Munstedt, Manthey, Sachsse, & Vahrson, 1997), breast (Frith, Harcourt, & Fussell, 2007; Lemieux, Maunsell, & Provencher, 2008; Mulders, Vingerhoets, & Breed, 2008), breast and lung (Rosman, 2004), and across cancer types (Carelle et al., 2002; Hilton, Hunt, Emslie, Salinas, & Ziebland, 2008; McGarvey, Baum, Pinkerton, & Rogers, 2001). Indeed, hair loss has been reported to be one of the most traumatic aspects of cancer treatment (Sun et al., 2005). For example, one prospective study found that 76.6 per cent of participants reported lowered self confidence after chemotherapy, with 46.6 per cent reporting hair loss to be the most traumatic aspect of treatment (Munstedt et al., 1997). Hair holds significant embodied meanings for femininity and sexual attractiveness (McGarvey et al., 2001), as well as defining facial features (Wilmoth, 2001). Furthermore, hair loss is often experienced as a socially visible signifier of the presence of cancer in one's

life (Rosman, 2004). Body hair loss was not discussed as often in the studies reviewed, possibly because body hair is often routinely removed or maintained as part of feminine bodily practices. One qualitative study found that when compared to men, women were more likely to talk about hair loss to their heads than other parts of their body and were also more likely to be encouraged by others to cover up their hair loss (Hilton et al., 2008). Further, as a form of management, a couple of qualitative studies described women cutting their hair off before losing it through chemotherapy as a way of taking control back from cancer and impact of treatment (Frith et al., 2007; Wilmoth, 2001).

### Body image and psychological distress.

Body dissatisfaction has been found to be related to lower emotional wellbeing and higher psychological distress (Andritsch, Dietmaier, Hofmann, Zloklikovits, & Samonigg, 2007; Fobair et al., 2006; Moreira et al., 2011; Reich et al., 2008). Further, depressive symptoms have been found to be a risk factor for poorer body image outcomes. For example, one study conducted with oral cavity cancer patients found that depression was a greater predictor of negative body image outcomes than impending surgery (Fingeret, Vidrine, Reece, Gillenwater, & Gritz, 2010). A prospective study conducted with women who had breast cancer found that depression at six months after surgery predicted lower body image scores at 12 months (Harcourt et al., 2003), while depressive symptoms at eight weeks post-diagnosis have also been found to be related to lower feelings of sexual attractiveness at 15 weeks post-diagnosis in women with breast cancer (Beckjord & Compas, 2007). In

another study conducted with men and women diagnosed with head and neck cancers, it was found that women and those with greater disfigurement reported higher rates of depression (Katz, Irish, Devins, Rodin, & Gullane, 2003). Given the value of body appearance embedded in social constructions of femininity (Bordo, 2003; Ussher, 1997a), it is likely that threats to sexual attractiveness from cancer may increase experiences of psychological distress for women.

As part of a call to assess body image as a multi-dimensional construct beyond evaluative responses towards the body (White, 2000), a few studies have examined investment as a cognitive 'trait-level' indication of the level of significance that body image concerns hold within an individual's selfconcept. Each of these studies has been conducted with samples of women who have breast cancer. In the first of such studies, investment in body appearance, being the extent to which appearance is important to self-concept, and investment in body integrity, being the extent to which body functioning and integrity are important to self-concept, were examined for their effects on psychological distress, psychosexual adjustment, and 'alienation from self' (Carver et al., 1998). Investment in body appearance was found to predict greater psychological distress prior to surgery and in the first 12 months postsurgery. However, investment in body appearance was also found to be a protective factor for psychosexual adjustment, with women who reported greater concerns about body appearance also reporting higher frequencies of sexual activity, greater feelings of sexual attractiveness and desirability, and lower levels of 'alienation from self'. Investment in bodily integrity was found to be related to disruption in psychosexual adjustment, with participants reporting lower levels of sexual desirability, frequency of sexual activity and greater 'alienation from self'. Petronis et al. (2003) replicated this study using a cross-sectional design with a larger and more ethnically diverse sample, and confirmed findings relating to body integrity, but not body appearance. Further, the effects of investment in body image integrity disappeared when distress was statistically controlled with the exception of lower frequency of sexual activity, suggesting that it is psychological distress that presents as a disruption to sexual practices for women with breast cancer.

A further series of studies have recently been conducted to examine the role of investment in body image outcomes (Moreira & Canavarro, 2010, 2012; Moreira, Silva, & Canavarro, 2010). These studies sought to examine the role of factors that comprise investment in body appearance and drive the processing of information relating to body image perception following cancer. The factors included motivational salience, conceptualised as the effort one puts into their physical appearance, and self-evaluation salience, conceptualised as the degree of importance physical appearance holds for self-concept. Motivational salience was found to be a protective factor and self-evaluation salience was found to be a vulnerability factor for psychosocial adjustment in all three studies. Specifically, motivational salience was related to higher levels of psychosocial adjustment and lower psychological distress, while self-evaluation salience was found to be a risk factor related to lower psychosocial adjustment and higher levels of body shame, self-consciousness and lower appearance satisfaction (Moreira et al., 2010). The authors suggest

that motivation to put effort into physical appearance contributes to a greater sense of control over appearance, buffering these women from adverse body image outcomes over time, particularly shame.

# Body image and sexual functioning.

Body image has been examined as a variable influencing the impact of psychological distress on sexual functioning after cancer, and as a perceptive construct through which women form affective and evaluative responses to the body, influencing experiences of sexual activity. Women with poorer body image report less sexual interest (Donovan et al., 2007; Ganz et al., 1999), and greater sexual discomfort (Liavaag et al., 2008). Furthermore, Green (2000) found that women who were not having sex at all after vulvectomy had higher rates of body image problems. Conversely, women with colorectal cancer who report a more positive body image also report higher levels of sexual functioning post-operation (da Silva et al., 2008).

While the associations between body image and sexual functioning beyond overall correlations were not examined in the studies reviewed, a literature review of non-cancer studies found that women's experiences of body image concerns can disrupt all aspects of sexual functioning (Woertman & van Den Brink, 2012). Particularly imperative to body image concerns and sexual functioning are affective states of self-consciousness and evaluative cognitions of the body. This study suggests that cultural imperatives associating ideal femininity with sexual attractiveness inform the likelihood of women viewing their own bodies as objects, and thus engaging in self-

objectification, increasing monitoring and greater consciousness of the body, rather than attending to sensory experiences during sex. Subsequently, physiological sexual responses are impaired and women report more disrupted desire, arousal and orgasm associated with body image concerns during sex (Sanchez & Kiefer, 2007). Further, women with a negative body image are also more likely to report avoiding sexual activity (La Rocque & Cioe, 2011). These findings resonate with those related to colorectal cancer and stoma surgery where the presence of a stoma can disrupt sex by contributing to anxiety and fear during sexual activity, as well as decreased sexual desire (Burns et al., 2007). Further, individuals often have to learn to manage visibility of a colostomy bag, sounds, smell, and fear of injury or dislodgement of the stoma during sexual activity (Weerakoon, 2001).

### Individual level factors.

In an effort to further understand the relationship between psychological distress, body image and sexual outcomes, some studies have examined individual-level age, cognitive and personality factors to further predict which women are more likely to be at risk from adverse sexual and psychological outcomes following cancer.

### Age.

Younger age has been identified as a significant risk factor for psychological distress in a number of studies. In the studies reviewed, 'younger' age was usually considered to be women who are pre-menopausal, or 45 years and younger. Women diagnosed with cancer during this time of

life report higher levels of psychological distress (Baucom, Porter, Kirby, Gremore, & Keefe, 2005; Burgess et al., 2005; Costanzo et al., 2007; Grabsch et al., 2006; Härtl et al., 2010; Turner, Kelly, Swanson, Allison, & Wetzig, 2005), fear of recurrence (Harcourt et al., 2003), distress related to impaired sexual functioning (Schmidt et al., 2005; Stewart et al., 2001), and reduction in overall quality of life following cancer (Arndt et al., 2004). Further, younger age has been found to predict more body image concerns and higher levels of body dissatisfaction (Avis et al., 2004; Fobair et al., 2006; Grabsch et al., 2006; Harcourt et al., 2003).

The psychological vulnerability of younger women has been attributed to medical, psychological and discursive factors. Firstly, younger women are more likely to be diagnosed with more advanced and aggressive tumours that are treated with stronger and more prolonged chemotherapy and radiation treatment, increasing the severity of treatment side effects (Beckjord & Compas, 2007; Ganz et al., 2004). As evidence of possible psychological factors, a couple of studies have suggested that younger women may be more likely to have less experience dealing with adverse life events than older women, leaving them more susceptible to psychological distress, while older women are more likely to be psychologically resilient and have more adaptive coping strategies (Lindau, Surawska, Paice, & Baron, 2011; Vos et al., 2004). Finally, suggestive of the influence of discursive factors, studies have also identified a relationship between disruption in role functioning and increased psychological distress in younger women (Hartl, et al., 2010; Arndt, et al., 2004), suggesting that when roles associated with femininity are disrupted,

such as those associated with family and work, increased psychological distress is experienced by younger women.

In contrast to findings regarding younger women, studies have found that older women experience more general physical symptoms and report a slower rate of recovery from cancer (Arndt et al., 2004). However, they also report lower cancer related anxiety and psychological distress (Parker et al., 2007), despite reporting lower sexual functioning (Likes, Stegbauer, Tillmanns, & Pruett, 2007; Milbury, Cohen, Jenkins, Skibber, & Schover, 2013) and a lower frequency of sex (Beckjord, Arora, Bellizzi, Hamilton, & Rowland, 2011; Green et al., 2000; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005). As such, older age has been identified as a protective factor for body image concerns, with older women reporting higher levels of body satisfaction (Parker et al., 2007) and self-esteem (da Silva et al., 2008), than younger women following cancer.

It has also been argued that the sexual concerns and desires of older women are yet to be fully addressed in studies on cancer and sexuality, with older women's sexual experiences often not accounted for at all in studies (Hordern, 2008). Studies outside cancer have found while many women report sexual changes following menopause, these are not necessarily experienced negatively, with some women reporting greater psychological and physical satisfaction from sex while reporting that sex occurs less frequently (Koch & Mansfield, 2002). In addition, some women, who are experiencing changes in their life situations (e.g. new partner or children leaving home), report more positive experiences of sex (Koch & Mansfield, 2002). Further, depression

and relationship quality are stronger predictors of sexual distress after menopause than issues with sexual functioning (Dennerstein et al., 2008), suggesting that despite the lack of acknowledgement, older women are likely to have more variable sexual experiences than those accounted for in the existing studies (Gannon, 1999).

## Sexual self-schema.

A few studies examined sexual self-schema as a variable influencing the relationship between cancer and sexual outcomes. 'Sexual self-schema' has been conceptualised as the generalised cognitive view of one's sexual 'self' (Andersen & Cyranowski, 1994; Cyranowski, Aarestad, & Andersen, 1999). People with a 'positive' sexual self-schema are more likely to value sex as important, be more sexually expressive, report a higher frequency of sexual behaviours, and form stronger romantic attachments (Carpenter, Andersen, Fowler, & Maxwell, 2009). In contrast, people with a 'negative' sexual selfschema are more likely to have lower levels of sexual desire, lower levels of sexual response, be avoidant of sexual behaviours, and fear relationship rejection (Carpenter et al., 2009). Sexual self-schema has been found to predict sexual outcomes following both breast and gynaecological cancers. Women with negative sexual self-schema are more likely to report lower rates of sexual activity, impaired sexual responsiveness and more susceptibility to stress related to body change (Andersen, Woods, & Copeland, 1997; Carpenter et al., 2009; Yurek et al., 2000). In addition, sexual self-schema has also been found to moderate the relationship between sexual outcomes and other aspects of psychosocial adjustment, as women with positive sexual selfschema are more likely to report lower psychological distress when sexual satisfaction is low (Carpenter et al., 2009). It has been theorised that women with more positive sexual self-schema are more likely to attribute sexual problems to sources external to self, compared to those with a negative sexual self-schema, who attribute sexual problems to internal sources (Cyranowski et al., 1999).

# Personality.

A few studies have examined trait dispositions associated with body image and sexual outcomes after cancer. One such study examined whether personality traits predicted investment in body appearance and body integrity (Lichtenthal, Cruess, & Clark, 2005). The following personality traits and relationships to investment outcomes were hypothesised; histrionic, being a tendency to be invested in the assessment of one's appearance by others; narcissism, being a tendency to overrate one's physical appearance; and obsessive-compulsive, being a tendency to maintain a controlled appearance. Histrionic personality traits were found to predict greater concern about appearance, and obsessive compulsive personality traits predicted greater concern about body integrity. However, no relationship was found between narcissism and body image investment, which the authors suggest was due to participants already being within the health system at the time of testing, meaning that their bodies had already been compromised due to tumours.

Other studies have looked at the influence of trait anxiety on sexual outcomes. The personality trait of agreeableness has been found to predict

more positive sexual adjustment 12 months post diagnosis in breast cancer patients, while trait anxiety predicted higher sexual dysfunction and lower sexual quality of life at 6 months (Den Oudsten, Van Heck, Van der Steeg, Roukema, & De Vries, 2010). Further, Van Esch, et al (2011) found that women who reported high levels of trait anxiety were also more likely to report lower body image outcomes and poorer sexual functioning following breast cancer. While trait anxiety is associated with psychosexual risk, it is possible that situational factors may also account for how sexuality is constructed and practiced in different relational contexts. Importantly, none of these studies contain measures of relationship quality, which may account for some of the findings in these studies (Andersen et al., 1997; Den Oudsten et al., 2010). Further, without positioning these findings within a wider discursive framework to account for the influence of wider cultural gendered dynamics, such studies risk pathologising individual women (Lafrance, 2009; Ussher, 2011).

### The intersubjective relational context.

Cancer can result in a range of physical, psychological and relational challenges, creating complex relational dynamics regardless of the quality of an existing relationship, (Emslie et al., 2009; Holmberg et al., 2001; Sprung, Janotha, & Steckel, 2011; Ussher, Wong, & Perz, 2011). Intersubjective frameworks have been used increasingly in research to more accurately account for changes in relationship dynamics and the individual outcomes of both partners (Feldman & Broussard, 2005; Ussher et al., 2011), concluding that both partners influence each other's coping strategies, psychological

distress and overall experiences of cancer (Badr, Carmack, Kashy, Cristofanilli, & Revenson, 2010; Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000). A couple of studies have drawn on the feminist theory of the relational self (Kayser & Sormanti, 2002; Kayser, Sormanti, & Strainchamps, 1999), arguing that women form their sense of self in relation to intimate others, meaning that women's experiences of cancer and sexuality are particularly sensitive to interactions within a relationship context. In support of this theory, the couple relationship has been shown to be an important part of adjustment to body and sexual changes for women with cancer (Altschuler et al., 2009; Brusilovskiy, Mitstifer, & Salzer, 2009; Wimberly et al., 2005), affecting the psychosocial adjustment of women past the acute phase of treatment and into recovery (Kayser & Sormanti, 2002).

### Sexual activity and couple relationship dynamics.

The vast majority of studies have examined sexual practices and outcomes within the couple relationship as the most prevalent context for sexual activity (Reese, 2011). As noted previously, levels of sexual activity tend to decline following cancer treatment (Andersen, 2009; Ganz et al., 1998). However, for many women and their partners, some level of sexual activity is resumed following treatment and into recovery (Jensen et al., 2004; Préau, Bouhnik, Rey, & Mancini, 2011). For some couples, prior levels of sexual activity and similar sexual practices are possible (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999; Stafford & Judd, 2010). For other couples, the frequency of sex, sexual pleasure, and overall quality and satisfaction of the sexual relationship is reduced post-cancer (Arora et al.,

2001; Çakmak, Aylaz, & Kuzu, 2010; Hawkins et al., 2009). For a number of couples, coital sex remains problematic and, in some cases, is no longer possible due to physiological and anatomical changes, or loss of sexual desire (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). In addition, women also report a decrease in non-coital sexual activities post-cancer, including sexual fantasy, kissing and caressing (Tang, Lai, & Chung, 2010).

In addition to the decline in sexual activity, many couples experience a decrease in intimacy within their relationships (Ussher et al., 2011), potentially threatening attachment within the relationship (Fobair & Spiegel, 2009). The quality of couple relationships has been found to provide a buffer, predicting sexual satisfaction while sexual dysfunction is still present (Ganz et al., 1999). Relationships that are particularly at risk for the disruption of sexual activity and intimacy are those where the partner has a pre-existing sexual problem (Ganz et al., 1999). Couples who are more flexible with their sexual practices and notions of 'sexual functioning' (Barsky, Friedman, & Rosen, 2006; Reese, 2011), and who engage in 'alternative', non-coital sexual practices (Gilbert, Ussher, & Perz, 2010a; Ussher et al., 2013), are able to renegotiate their sexual relationships with more success than those who adhere to the notion of non-coital sexual practices as not 'real' sex, or as a precursor to sex. Along with this, couples who place a stronger emphasis on intimacy through non-sexual physical touch and communication also show stronger relational adjustment following cancer (Reese, 2011). For some couples, maintaining their sexual relationship, despite complications, can be a way of

maintaining normalcy during their experience with cancer (Lindau et al., 2011).

Relationship dynamics can be affected by the cancer experience, changing sexual dynamics and outcomes for couples. For example, the experience of illness may result in the partner positioning the women with cancer differently in their relationship, through a parent-child dynamic in the relationship (Fergus & Gray, 2009), or as a patient, particularly when the partner is taking on a carer role (Gilbert, Ussher, & Hawkins, 2009). Both of these examples may serve to de-sexualise the woman with cancer and disrupt sexual dynamics within the couple relationship. Some studies have also described partners doing communicative and emotional work to protect the person with cancer from their own needs, desires and challenges through the cancer experience. For example, a partner may take on a protective role, where the focus of the relationship is on the person with cancer (Fergus & Gray, 2009), rather than the needs of the carer, including sexual needs. Further, changing gender roles within the household that differ to usual role functioning in the relationship, such as men taking on more non-traditional caring roles (Maughan, Heyman, & Matthews, 2002), may require adjustment, impacting on relational and sexual dynamics for a couple.

Despite there being fewer studies that have examined the disparities in relationship dynamics and sexual outcomes between partners (Ussher et al., 2011), there is some evidence that these disparities do exist (Manne et al., 2006). For example, women with gynaecological cancers report sexuality concerns more than a year after treatment, as opposed to male partners who

report these concerns close to treatment, but not into recovery (de Groot et al., 2005). Further, women have also reported higher levels of vaginal narrowing and dryness following treatment for gynaecological cancer, and lower rates of satisfaction with their physical appearance than is recognised by their partners (Stafford & Judd, 2010). Qualitative research has described male partners' difficulties in adjusting to disfigurement and scarring following a mastectomy (Ussher et al., 2012), which may result in men not wishing to touch or see the mastectomy site due to perceptions of their partner's body as less feminine and sexually attractive (Sawin, 2012; Yeo et al., 2004). Another study on partners of men and women with colostomies after surgery for rectal carcinoma found that 20 out of 26 male partners of women reported that they were no longer sexually active with their partner a year or more after treatment (Çakmak et al., 2010). Eighty per cent of these participants reported that the main reason for the absence of sexual activity in their relationship was that they found their partner's colostomy "repulsive" (p. 2874).

# Women's bodies, the sexual 'self' and the couple relationship.

The quality of the couple relationship has been found to act as a buffer for detrimental psychological effects and sexual changes for women following cancer (Kudel, Edwards, Raja, Haythornthwaite, & Heinberg, 2008; Moreira et al., 2011; Tang et al., 2010). Specifically, feeling accepted, desired and supported by one's partner can help women to adjust to these changes following cancer (Altschuler et al., 2009). Partner initiation of sex has been found to be related to greater marital satisfaction following breast cancer, while adverse partner reactions to the surgery scar predicts less marital

satisfaction (Wimberly et al., 2005). Women who report higher levels of marital quality and intimacy in their relationships also report higher levels of physical quality of life and fewer body image concerns (Moreira et al., 2011). These findings resonate with results that suggest that higher levels of relationship agreement encourage increased perceptions of social support, which are in turn, related to feelings of physical attractiveness (Abend & Williamson, 2002). In addition, it has been found that higher perceptions of men's relationship satisfaction by women predict higher levels of selfacceptance of women's own body image (Zimmermann, Scott, & Heinrichs, 2010). Further, partner support is considered important by women when adjusting to an ostomy prosthetic bag as a result of cancer, with women describing good support as involving giving assurances about their bodies, femininity and sexual desirability, and using language that was comforting and normalised the ostomy (Altschuler et al., 2009). These findings suggest that women's perceptions of their bodies and selves as 'desirable' and 'sexual' are shaped by relational context, making women particularly susceptible to the influence of the relationship on their own psychosexual adjustment.

# Single women and sexuality.

Very little research has examined experiences relating to sexuality and body changes of women who are single post-cancer (Hordern, 2000). Existing studies have tended to focus on marriage, or 'marriage-like' relationships, which are usually defined as couples who have lived together for a least a year. The number of people in Australia who are unpartnered, or who are in a relationship, but live separately, has increased over time (ABS, 2009).

Evidence also suggests that the relationship trajectories of women have become increasingly complex (ABS, 2009; Cohen & Manning, 2010). Further, younger women are more likely to be single, or in a newer relationship at the time of a cancer diagnosis (Adams et al., 2011), which can be an important consideration in the context of a significant relational stressor such as cancer, and potential disruption to a future sexual relationship. Little is currently known about sexual and relationship trajectories taken up by women who are single or not in a long-term relationships following cancer. As many of the findings from existing studies stress the importance of relational contexts for women's sexual and psychological outcomes after cancer, the experiences of single women in the absence of a long-term relationship are important to consider.

Single women have been found to be more at risk of impaired psychosocial adjustment and depression compared to partnered women after cancer (Meyerowitz et al., 1999). One qualitative study found that unpartnered women were particularly vulnerable following cancer without the buffer of an intimate relationship, which is partly suggested to be due to the absence of an intimate partner to disclose cancer-related concerns (Holmberg et al., 2001). Single women have reported greater feelings of embarrassment, concern about sexual attractiveness, concerns about weight loss or gain (Fobair et al., 2006) and poorer body image (da Silva et al., 2008). Many single women may be interested in a relationship (Avis et al., 2004; Ganz et al., 1998), however they encounter barriers including fears about the future impact of cancer on one's ability to meet a partner, initiating a sexual relationship, when to tell a new

partner about their cancer and how much to disclose, and the possibility of rejection due to body changes and a cancer diagnosis (Ramirez et al., 2010). For women who have already experienced sexual rejection as a result of sexual changes and the stress of cancer, emotional pain from past relationship experiences may also be a barrier to entering a new relationship (Holmberg et al., 2001; Ramirez et al., 2010).

Existing studies tend to position the sexual and psychological concerns of single women according to their age and the developmental tasks associated with particular life-stages. Adolescents and young adults diagnosed with cancer are more likely to be at a stage in life when their sexuality is developing and they are experimenting with sex and sexual relationships (Zebrack, 2011). A diagnosis of cancer at this stage in life can impair psychosexual development and is related to lower rates of engagement in sexual activities into adulthood (van Dijk et al., 2008). In addition, younger single women may have to contend with premature menopause, impaired sexual desire and arousal (van Dijk et al., 2008), infertility (Howard-Anderson, Ganz, Bower, & Stanton, 2012), and challenges to developing body image and confidence with sexuality (Tindle, Denver, & Lilley, 2009). These experiences may inhibit developing identities and sexualities, and have to be negotiated following a cancer diagnosis and into recovery.

Meanwhile, sexuality and seeking a partner has not been considered as important for older women in many studies, which is reflected in the absence of post-menopausal, single women from some studies (Hordern, 2000).

Further, health professionals may assume that sexuality is not important for

older women (Hordern, 2008). Women who are not currently sexually active, do not have a partner prior to cancer, and who remain unpartnered post-cancer, may not report quantifiable effects on sexual outcomes according to the measures used in studies (Meyerowitz et al., 1999). However, this does not account for how these women may be feeling about, or experiencing sexual changes following cancer. One qualitative study examined this issue in more detail and found that single women were going through particular processes when coming to terms and making meaning of their singleness and sexuality following cancer (Ramirez et al., 2010). For these women, processing their cancer experiences meant moving towards an acceptance of now being celibate, prioritising survival over sexuality, and positioning a sexual relationship as something that may have been for an earlier time in life. However, more research is needed in this area to fully understand the sexual needs and desires of older women not in long-term heterosexual relationships after cancer.

# Critique of Biomedical and Psychological Research on Cancer and Sexuality.

A discursive critique was conducted on the studies reviewed in which dominant discourses of heterosexuality and femininity that have shaped the production of knowledge in the area of women's sexuality and cancer were identified. Without an integration of discursive critiques, such studies risk implicitly reinforcing cultural structures that shape women's experiences (Lafrance, 2009). Further, applying a discursive critique to existing research may allow greater visibility as to how the social structures inherent in cancer

research and practice also contribute to women's experiences of embodied sexuality. The following section will examine the influence of the discursive structures of heterosex, heterosexual relationships and feminine subjectivities, and finally, the positioning of psychological distress as a feminine risk and individual pathology. These constructs are interrelated and contribute to the production of the hetero-feminine discourse that dominate social constructions of 'sex', femininity, allocations of psychological and sexual 'risk', and the positioning of sex within long-term heterosexual relationships.

#### 'Sex' and hetero-feminine bodies.

A material-discursive-intrapsychic theoretical approach would consider that while the corporeality of body changes contributes to women's sexual experiences after cancer, the materiality of the body is not experienced separately from discursive meanings and context. In this vein, the majority of research studies reviewed examining women's sexual functioning adopted 'normative' discourses of heterosexuality, positioning heterosex as coital sex (Gilbert, Ussher, & Perz, 2013; Hyde, 2007; Ussher et al., 2013; White, Faithfull, & Allan, 2013). Positioning 'sex' in this way can to be seen as part of the coital imperative, where acts of penile-vaginal penetration are positioned as 'sex' (McPhillips et al., 2001). As such, coital sex is constructed as 'real' sex and non-coital sexual activities positioned as 'alternatives' or 'precursors' to coital sex. Further to this, biomedical definitions of female sexual 'dysfunction' are structured by the coital imperative with 'dysfunction' defined according to the physical ability and willingness of individual women to engage in coital sex (Tiefer, 2004). As such, the vast majority of the studies

reviewed reflect biomedical definitions of sexual 'dysfunction', placing emphasis on sexual 'functioning' after cancer, and subsequently, on the restoration of the sexually 'functioning' body, specifically the vagina (White et al., 2013), to the exclusion of other sexual practices (Hyde, 2007).

By adopting a biomedical discourse, the majority of existing studies construct 'sex' as a 'natural' property of the female body, and something that is 'essential' and 'unmalleable' (Zita, 1998). Such definitions are binary in nature, constructing the body as 'functional' or 'dysfunctional', 'normal' or 'abnormal' (Tiefer, 2004). Through the use of these discourses, individual women risk being pathologised with a diagnosis of sexual dysfunction due to physical changes that may impact upon their ability to practice coital sex, and the absence of desire or motivation toward sexual activity after cancer (Drew, 2003). An acknowledgement of the discursive construction of 'sex' in the area of cancer and sexuality would allow studies to examine how women account for their sexual subjectivity in a way that may shed light on how the coital imperative shapes women's embodied sexual experiences after cancer. It would also allow for the inclusion and validation of a greater diversity of sexual practice, which may hold particular importance in instances where coital sex is no longer physically possible or desired following cancer (Ussher et al., 2013).

The structure of emphasis on particular body changes covered by the studies reviewed was evidence of embodied discourses of hetero-femininity (Bordo, 2003; Ussher, 1997a). Existing studies have focused on breast cancer, gynaecological cancers and, to a lesser extent, colorectal cancers, focussing on

changes to the vagina and sexual arousal that are directly implicated in the act of coital sex (Hyde, 2007), and disruption of visible bodily markers of femininity, most specifically the breasts (Langellier & Sullivan, 1998; Young, 2005). However, studies that examined sexual issues experienced by women with lymphoma, head and neck and lung cancers suggest that women who are diagnosed and treated for other types of cancers are also likely to experience changes to their bodies and sexual functioning, that threaten femininity and experiences of 'sex' (e.g. Beckjord et al., 2011; Lindau et al., 2011; Low et al., 2009). The focus on cancers associated with the act of coital sex and visibility of femininity also reflect a cultural construction that women's sexuality is an experience associated with particular compartmentalisable aspects of women's bodies, namely the breasts and vagina, contributing to the construction of women's sexual bodies as 'object', rather than considering sex as a subjective, whole body experience (Young, 2005). Further questions remain about how women experience changes to their sexuality from the perspective of a range of different cancers. Currently, there is a lack of studies that have examined the experiences of women across cancer types to determine what is of commonality to women's experiences of 'femininity' and 'sex' across cancer types and cancer treatments. The use of an across cancer type sample, as was adopted in this study, can allow for the observation of discursive factors and processes that are common to women's experiences of embodied sexual subjectivity after cancer, or which may differ across cancer type.

### Heterosexual relationships and feminine subjectivities.

Currently, most of the studies that examine women's experiences of sexuality following cancer fail to critically engage within the context of gender power relations that influence relational dynamics and sexual practices within heterosexual relationships (Hyde, 2007). For example, one study reported earlier in this review found that the vast majority of women had resumed sexual activity one year after treatment, despite reporting ongoing problems with lack of sexual interest and vaginal lubrication (Jensen et al., 2004). While some studies might report such a finding as an example of sexual resilience (e.g. Greenwald & McCorkle, 2008), further questions could be asked about why women are engaging in coital sex despite reporting a lack of sexual interest and problems with vaginal dryness. Examining this finding in light of the coital imperative, discussed previously, would suggest that coital sex is an implicit expectation in heterosexual relationships (Potts, 2002). Further, women in long-term heterosexual relationships report having sex for relational reasons (Hayfield & Clarke, 2012), with some women also reporting having sex despite experiences of pain and the loss of sexual desire (Hinchliff, Gott, & Wylie, 2012). Such findings are consistent with a 'good woman' subject position, in which women privilege the needs of others before their own needs (Jack, 1991). Consideration of expectations around coital sex as taken-for-granted in heterosexual relationships are particularly important in light of findings discussed earlier that suggest that the context of the couple relationship is a significant 'buffering' factor for women's psychological

distress after cancer (e.g. Kudel et al., 2008; Moreira et al., 2011; Tang et al., 2010).

Hetero-feminine subjectivities are strongly structured around heterosexual relationships (Reynolds, 2008; Ussher, 1997a). As discussed earlier, studies that have examined sexual outcomes and concerns correlated with women's ages, tend to view such findings within 'normative' developmental frameworks. Developmental frameworks tend to be formulated around 'goals' that are associated with particular stages of life, with heteronormative constructions of relationships featuring strongly in developmental goals structured around dating, securing a committed long-term heterosexual relationship and having a family (Reynolds, 2008). The importance of a being in a long-term relationship to hetero-femininity is stressed, as well as the ability to perform family, relationship and employment roles associated with the performance of feminine subjectivities. Such discursive structures reflect dominant discourses of heterosexuality where securing a man and long-term relationship are important to taking up culturally desirable feminine subjectivities (Ussher, 1997a). In contrast, single subject positions for women tend to be defined by "lack" (Reynolds & Taylor, 2005, p. 198), specifically the absence of a male partner, with single women often finding themselves at risk of being positioned as undesirable and unattractive (Reynolds, Wetherell, & Taylor, 2007). The absence of women who are not in a long-term heterosexual relationship in the current studies reflects the cultural construction of single women as 'lacking' a 'legitimate' feminine sexual subjectivity.

Despite the increasing diversity in life histories and relationship trajectories (ABS, 2009), as noted above, current studies within psychooncology tend to reinforce social constructions of single women by confining sex to long-term heterosexual relationships, tending only to include couples who are married or who have been living together for a year or more in analyses (Hordern, 2000). Women who have sex outside of this context, or who may not have a sexual partner at a particular point in time tend to be excluded from this research. By implication, women without male partners, women who experience greater fluidity between sexual relationships, and women who have more than one sexual partner, are not adequately accounted for in existing studies.

## Psychological distress as feminine risk and individual pathology.

As discussed previously, the rate of women's psychological distress after cancer has been found to be up to two times that of the non-cancer population (Grabsch et al., 2006; Härter et al., 2001; Reich et al., 2008), with distress continuing for a proportion of women (Härter et al., 2001), many of whom have a history of anxiety and depression (Burgess et al., 2005; Reich et al., 2008). Findings on women's psychological distress and cancer need to be considered in the context of broader non-cancer studies in which female gender is positioned as a risk factor for psychological distress. For example, women are twice as likely as men to report experiencing psychological distress and receive a psychiatric diagnosis, most commonly for affective and anxiety disorders (Bebbington, 1996; McLean, Asnaani, Litz, & Hofmann, 2011). Feminist researchers have placed the responsibility for the prevalence

of psychological distress on oppressive social structures, contributing to experiences of accumulative stress, unrealistic expectations of gender role performance, and emotional regulation (Jack & Ali, 2010; Lafrance, 2009; Stoppard, 2000; Ussher, 2011). A discursive approach to psychological distress in the context of cancer would consider the impact of cancer as a stressful life event with consequences for the sexual and relational aspects of women's lives, within the context of broad cultural structures and dynamics that contribute to women's experience of psychological distress.

Studies within psycho-oncology have used measures of 'body image' to understand the psychological consequences of body change as a result of cancer. The findings of these studies provide important information that signal particular psychological responses from women to the changes to their bodies, in particular evaluations of dissatisfaction or satisfaction towards the body, and affective responses such as body shame. Women, and particularly younger women, are considered at higher 'risk' of body image problems within the general population (Kostanski & Gullone, 1998). Currently, very few studies link the experiences of women following cancer within a broader cultural framework, which would position risk of body dissatisfaction as an aspect of gendered experience. To do so would acknowledge the discursive meanings and practices associated with women's bodies, including the valuing of women's bodies according to ideals of sexual attractiveness and consideration of how femininity is performed in terms of gendered body practices (Bordo, 2003). In this vein, the lowering of body image scores following cancer indicates some changes that occur for women following cancer treatment,

which may further challenge existing experiences. However, currently the 'risk' of body dissatisfaction and associated affective states is positioned largely as a product of the 'minds' of women who experience cancer (Malson & Nasser, 2007), or through further analysis of individual variables, as a product of women's 'investment' in their physical appearance (Moreira et al., 2010). A discursive approach would examine these experiences as they occur within socio-cultural contexts and the influence of discursive factors in shaping the relationships women have with their bodies.

Blood (2005) takes this argument further, arguing that body image is a discourse that not only describes a particular relationship between women's bodies and 'selves', it also actively contributes to the objectification of women's bodies. Cultural constructions of women's bodies are enacted and reinforced through body image research, inviting a social action in which the body is the object of a gaze upon which assessments of perception, evaluation and emotional responses are drawn. Certainly, in addition to the absence of gendered socio-cultural context, the research reviewed did not tend to conceptualise the body as subjective, as desiring, or with an unconscious (Blood, 2005). As such, the subjective experience of embodiment, as embedded within socio-cultural context, is yet to be fully addressed in psychooncological studies of women's experiences of cancer and sexuality.

The consideration of discursive factors that contribute to women's experience of changes to body image and psychological distress has implications for findings related to younger women. As discussed earlier, younger age was a significant risk factor for adverse outcomes relating to

psychological distress and body image following cancer identified in the studies reviewed (e.g. Baucom et al., 2005; Grabsch et al., 2006; Härtl et al., 2010). Such findings are also reflective of non-cancer studies on women's body image and psychological distress, where younger women report higher rates of body dissatisfaction (Kostanski & Gullone, 1998), awareness of the male gaze, and greater monitoring and regulation of the body (McKinley, 2011). While the studies reviewed offered explanations in the form of medical, psychological, and discursive factors in the sense of 'role functioning', further analysis of the discursive context of women would acknowledge that younger women tend to be more visible within the male gaze (Calogero, 2004; Hine, 2011). As such, the male gaze is often internalised by women, structuring perceptions of their own attractiveness and the importance of maintaining attractive bodily practices against idealised discourses of feminine beauty (Bordo, 2003). As a result, consideration of discursive factors would allow cancer researchers to acknowledge the cultural dynamics that produce idealised discourses of feminine beauty, as well as shifting the emphasis in problematising women for being subject to these discourses, to the cultural structures through which these dynamics function.

# Discursive Constructions of Women's Sexuality and Cancer

This section examines studies that have employed a discursive construction of cancer and body changes that relate to women, including studies that have examined subjectivities relating to 'cancer', 'survivorship', 'femininity', and 'heterosexuality'. These studies emphasise the subjective meaning making that women with cancer engage in around their illness

experiences, including body changes, interactions with the medical system, and life after treatment.

# Cancer subjectivities.

Studies informed by discursive constructionist approaches have examined the way that women make sense of their 'selves' in relation to their experiences of cancer. Many studies have described accounts of cancer in terms of a biographical disruption, saying that cancer disrupts constructions of 'self', through problematic bodily functioning, disruption to social roles, and greater awareness of mortality (Hubbard & Forbat, 2012; Laranjeira, Ponce Leão, & Leal, 2013; Little et al., 2002; Mathieson & Stam, 1995). As such, cancer narratives tend to be characterised by experiences of uncertainty, risk, and the loss of control (Kaiser, 2008; Thomas-MacLean, 2004b; Wiener & Dodd, 1993). These experiences provide challenges to people with cancer when making sense of their experiences in terms of continuity between past and present 'selves'. As a result, such studies have examined how people construct their subjectivities in the context of cancer, exposing variations in how women make sense of their 'selves' in relation to dominant discourses of 'survivorship'. For example, it has been argued that the most socially dominant constructions of cancer experiences, including those contained within information distributed by the medical system, portray women with cancer as staying positive, adhering to medical treatments, and drawing on inner resources to overcome the threat of cancer (Davis, 2008). In these narratives, the event of cancer becomes an opportunity for posttraumatic growth (Bell, 2012). While it is important to acknowledge the legitimacy of

women's experiences to adopt such narratives, many other women report experiences that are more chaotic and problematic due to ongoing physical and psychological consequences (Thomas-MacLean, 2004b). Such experiences can create difficulty taking up dominant discourses of health and wellness, leading some researchers to conceptualise these constructions of subjectivity as 'liminal' (Blows, Bird, Seymour, & Cox, 2012; Little et al., 1998).

### Discursive meaning making of body changes.

Discursive approaches to women's experiences of cancer have been used to examine the meanings that women have made of the changes to their bodies. For example, one study examined women's experiences of gynaecological cancers, and found that there were differences between types of cancers, based on the availability of cultural meanings to make sense of women's sexual and reproductive organs (Wray, Markovic, & Manderson, 2007). Women with vulva and vaginal cancers, that is cancers that are associated with 'sexual' parts of the body, reported experiencing a disruption between the positioning of their bodies as 'sexual' and 'private' in the context of medical examinations and cancer treatments. They also found it more difficult to name their cancer to others due to the lack of language available and stigma. Subsequently, these women were less likely to take up 'normative' cancer discourses and less likely to seek social support through cancer networks compared to women who were diagnosed with cancers of reproductive organs. In another qualitative study, biomedical and discursive constructions of embodied feminine sexuality were examined in the accounts

of medical clinicians, and women who had received pelvic radiation treatment (White et al., 2013). It was reported that the women found it difficult reconciling the biomedical meanings of their vaginas as affected by cancer and treatment, with private and sexual meanings, reporting experiences of distress and challenged constructions of femininity. Further, clinicians tended to desexualise the women's vaginas, employing biomedical discourses by speaking of the women's vaginas only in terms of receptivity for penetration during coital sex.

In an example of the discursive meanings of breast cancer, Langellier and Sullivan (1998) described the multiple meanings that women made of their breasts, when speaking about breast cancer and breast cancer treatments, including surgery. The women positioned their breasts through the following discursive constructions: 'medicalised' discourses, which positioned the women's breasts as diseased, subject to medical treatment, and separate from constructions of femininity and sexuality; 'functional' discourses, which emphasised the role that breasts have in breastfeeding and assisting in balance and mobility; 'gendered' discourses, which positioned breasts as indicators of femininity in social contexts; and 'sexual' discourses, which positioned breasts part of sexual activity. This study indicates the multiplicity of meanings that are subjectively made of breasted experience by women (Langellier & Sullivan, 1998), beyond the meanings dominant in Western cultural contexts, particularly those of breasts as sexual objects (Young, 2005). In another study, Manderson and Stirling (2007) examined how women constructed the loss of their breasts and mastectomy sites. The women moving between speaking of

the body as 'self' and 'other', as well as 'subject' and 'object' in their accounts. As such, the accounts demonstrated the women's difficulties referring to the "presence" of a "bodily absence" (Manderson & Stirling, 2007, p. 82), with a tendency to adopt passive constructions of their breasts during cancer treatment, and report experiences of self-consciousness with their reconstructed, or surgically changed breasts.

Some studies have examined the discursive constructions of experiences of the loss of control of the body following cancer, and treatments used to treat cancer (Manderson, 2005; Rozmovits & Ziebland, 2004; Waskul & van der Riet, 2002). For example, in one qualitative study (Manderson, 2005), the loss of control of the body experienced by people with an ostomy contrasted with desirable discourses of sex due to the ongoing management of their bodies during sexual activity. Similarly, another study examined how the loss of control and breach of bodily boundaries associated with bowel dysfunction after colorectal cancer, was associated with challenges to 'adult' subjectivities due to bodily experiences that were in opposition to the control over the body that is part of adulthood (Rozmovits & Ziebland, 2004). This study found that these disruptions were subsequently associated with lowered feelings of sexual confidence. Finally, a further study examined the relationship between bodily experiences and the constructions of subjectivity in the context of 'abject' embodiment (Waskul & van der Riet, 2002). 'Abject' bodies were those that were uncontained and breached bodily boundaries, both materially and symbolically. Again, this study also demonstrated participants moving between positioning the body as 'self' and 'other', as well as engaging in bodily practices, including humour, to manage bodies that were out of control.

# **Chapter Conclusion**

The review of the literature conducted revealed that women experience a range of psychological and body changes following cancer, which can impact on their sexual functioning and wellbeing. Particularly pertinent in the studies reviewed were corporeal disruptions to coital sexual functioning, increased psychological distress, lowered body image and sexual attractiveness, as well as disruptions to sexual and relational dynamics. I argued that it is important to also consider discursive structures and dynamics to avoid pathologising individual women for the implications of oppressive cultural structures. Further, the discursive studies reviewed indicated that bodily experiences and discourses that surround cancer, femininity and heterosexuality can inform the construction of subjectivity, revealing multiple, dynamic constructions of 'self' that are not separate from cultural context. As such, the importance of considering the subjective experiences of women is emphasised, particularly in terms of how the issues covered in the review are experienced in everyday life, and as part of discursive contexts. Theoretical perspectives that allow for acknowledgement of the corporeality of the body after cancer, the discursive context and dynamics that inform subjectivity, and the intrapsychic experience of cancer and embodied sexual subjectivity will be considered in Chapter Three.

## **Chapter Three: Theorising Embodied Sexual Subjectivity**

The review of theoretical literature in this chapter centred on two questions: How do different theoretical perspectives theorise the body and embodiment? And, how do different theoretical perspectives theorise subjectivity? Both of these questions are deeply interrelated and have important implications for the theorisation of gender and sexuality, particularly in the context of the current study with a focus on women's embodied sexual subjectivity in the context of cancer. The literature reviewed for this chapter was selected from theory that has informed critical approaches to psychology, primarily poststructuralism, discursive psychology, and psychoanalytic theory used by 'psychosocial' researchers, who also employ a poststructuralist theorisation of the socio-cultural. Each of these approaches has employed different theoretical arguments and emphasis to acknowledging the discursive, material and intrapsychic aspects of embodied subjectivity. The theoretical perspectives reviewed in this chapter differed in the extent to which the materiality of the body was emphasised through discourse, or the extradiscursive, and how intrapsychic dynamics were addressed and emphasised. Such differences have important theoretical and methodological implications for this study.

Previous research on aspects of women's experience of cancer and sexuality has been reviewed in Chapter Two. The literature reviewed in this chapter provides background and context for the material-discursive-intrapsychic theoretical framework, and critical realist epistemology, adopted for the study. Due to the extra-discursive materiality of cancer, it was decided

that drawing on a framework that acknowledged the materiality of the body as contributing to the conditions of subjectivity was important. Further, intrapsychic experiences of emotion, distress, cultural meanings and subjectivity were considered important indicators of the experience of embodied sexuality for women after cancer.

Materiality and the intrapsychic cannot be conceptualised outside of the discursive construction of sex, heterosex and sexual subjectivity. The current chapter will therefore review poststructuralist discursive approaches to subjectivity and embodiment, including firstly, poststructuralist conceptions of language, discourse, power, the body and embodied practices. Secondly, psychoanalytic theories and approaches as they have been employed by poststructuralist and psychosocial researchers to address the intrapsychic dynamics of subjectivity will be covered, including Lacanian, and object relations and relational psychoanalysis perspectives. These theories are included due to their acknowledgement of the discursive and intrapsychic and their use within critical psychology. Finally, material-discursive and material-discursive-intrapsychic theoretical approaches will be reviewed as theoretical frameworks that emphasise the extra-discursive materiality of the body.

There are limitations to structuring the theoretical review in this manner as different streams of theoretical thought within poststructuralism have influenced others, or may be used in combination, and do not always separate into categorical sections. However, such influences characterise the formation of poststructuralist thought and have influenced research practices informed by poststructuralist theory (Henriques et al., 1984; Weedon, 1997).

#### Poststructuralism, Subjectivity and Embodiment

Poststructuralist theorists argue that social reality is produced within language (Weedon, 1997). This position means that social organisation, representations of reality, and meanings of experience are all deemed to be products of social interaction. As such, accounts of subjectivity are not separate from the social context in which subjectivity occurs (Henriques et al., 1984). Further, social contexts shape subjectivity in ways that are both productive and limiting (Gavey, 1989). In theorising how this occurs, poststructuralist thought has drawn heavily on Saussure's theory of the 'sign' (1974). According to this theory, language takes the form of a 'sign', with the 'signifier' being the sound produced and the 'signified' being the meaning associated with the sign. However, meanings are not fixed, but are dependent on the context in which signifiers are used. Shared social meanings are referred to within poststructuralist approaches as 'discourses' and are organised by social structures, present in the privileging of some discourses over others, in accordance with the social organisation of meanings (Foucault, 1980). The privileging of particular discourses can change over time and across social contexts, stressing the importance of particular historical and cultural locations of discourse (Foucault, 1984). Such a position recognises the materiality of cultural imperatives, social and institutional structures and everyday embodied experiences. However, such a materiality is not separate from language. Poststructuralism has drawn on several theorists, in particular Foucault and his theory of language, knowledge, and power (Foucault, 1980),

which theorises intimate connections between localised embodied actions and 'bigger picture' power structures within society (Foucault, 1984).

Poststructuralist theorists refer to individuals as 'subjects', accounting for experiences, senses of 'self', and identities within a model of 'subjectivity', which is a process of constant and dynamic change (Weedon, 1997). Subjects produce subjectivity through the use and negotiation of the different discursive positions available to them within the bounds and possibilities of particular language contexts. The main idea behind these concepts and their application in research is to de-centre the 'self' by collapsing the distinction between self and society (Sarup, 1993), extending possibilities when considering who we are and what we do as social beings, and conceptualising subjects as non-unitary and irrational (Henriques et al., 1984). Subjects negotiate meaning making of 'self' in relation to their social environments by taking up subject positions made available through social discourses (Harre & van Langenhove, 1999). Subject positions are often competing and conflicting, with subjects experiencing a multiplicity of 'selves' across social contexts (Harre & van Langenhove, 1999). By implication, subjectivity within poststructuralism is fragmented, plural and dynamic (Henriques et al., 1984). Such a position also has socio-political implications for subjectivity, as issues such as oppression, pathology, and 'personal conflicts' are viewed as being facilitated by social discourses within particular cultural contexts, rather than the product of an individual's body or psyche (Gavey, 2011). There are strengths to this position when considering

research in cancer and sexuality, where cultural discourses significantly shape meaning-making of embodied experiences and sense of 'self'.

A further central tenant of poststructuralism, is an analysis of power and power relations (Weedon, 1997). Poststructuralist approaches draw on Foucault's theories of discourse, knowledge and power (Foucault, 1984; Sarup, 1993). According to Foucault, power is relational (Weedon, 1997), produced continually within social relations, rather than purely hierarchical (Foucault, 1980). From this perspective, it is impossible to make sense of power without an understanding of the production of knowledge and the relationship between the two (Barker, 1998; Foucault, 1980). According to Foucault, the production of knowledge produces power and, simultaneously, the production of power produces knowledge. However, not all forms of knowledge are valued equally in social contexts and, among the plurality of meanings available in discourse, there is a hierarchy that privileges of some forms of knowledge over others (Foucault, 1972). Foucault's theorisation of the relationship between knowledge and power is a socially active one, and he proposes that as power is produced, so opportunities for resistance are also created. There are a range of different discursive strategies that subjects can employ to produce power, and in doing so, can also create new and subversive meanings that act as sites of resistance (Spence, 1995). This means that in the production of power, subjects are simultaneously both objects, and subjective agents, of power (Barker, 1998).

Embodiment in poststructuralism is viewed primarily through discourse, inseparable and unable to be accessed outside the structures of

meaning inherent in language (Sarup, 1993). There is no body outside of our ability to make sense of the body and, therefore, there is no body outside of language. Or, in other words, the 'matter' of the body is brought into 'being' through language (Butler, 1993). The body is the object of cultural discourse, inscribed with meanings and constantly viewed socially, through cultural lenses (e.g. Potts, Gavey, & Weatherall, 2004). 'The body', in a socially constructed sense, like subjectivity, is not a unitary, essential, or 'natural' entity, but fragmented, plural, and produced through acts of subjectivity. This position has been criticised by some social constructionists who emphasise the materiality of the body as 'extra-discursive', for positioning actual embodied experiences as discursive events, rather than dealing with 'actual' bodies and bodily experiences (Cromby, 2005). The implications of this criticism will be discussed further in the section in this chapter on material-discursive approaches to embodiment and subjectivity.

Western cultural discourses of embodiment are structured by dualisms that form binary opposites, including mind/body, subject/object, nature/culture, public/private, presence/absence and outer/inner (Potts, 2002). According to the cultural organisation of shared social meanings, one side of the binary is privileged over the other. Masculine qualities tend to be associated with privileged terms that transcend the body, such as mind, subject, nature, public, presence, and outer. Feminine qualities tend to be closely associated with the body and positioned in terms of a 'lack' of the privileged binary opposite, including the body, object, culture, private, absence and inner. As such, embodiment has been conceptualised in terms of

the 'spaces' that men's and women's bodies occupy, both in cultural discourse and in embodied experience and practice. For example, where heterosexual men legitimate their masculinity by enacting sexual acts 'out' into the world, such as engagement in coitus, women's sexuality has been conceptualised as an 'inner' experience. Women are positioned as being receptive in the act of coitus, their sexuality constructed as an internalised, less visible and a more complex experience. Furthermore, as part of the association of femininity with the body, women's bodies are viewed as 'object'. Aspects of feminine corporeality are socialised as requiring containment, such as the leaking of fluids that may breach bodily boundaries, as well as the space that women's bodies literally take up, such as the crossing of legs. As a consequence, aspects of women's corporeality remain constructed as 'private' with women's bodies never quite occupying 'space' as an assumed and visible presence, remaining problematic. As such, women are more likely to experience their corporeality as 'other', even to themselves.

Such constructions serve to maintain power differentials between men and women, by producing the notion of unity as the combination of opposites, rather than producing new and different frameworks of meaning (Potts, 2002). Dualistic discourses of the body structure the meanings that are employed by subjects to make meaning of embodied experiences (Bordo, 2003). Some feminists interested in embodiment and sexual difference have drawn on metaphysical theories of language to deconstruct binary opposites and reformulate theories of embodiment that recognise sexual difference. Such approaches often draw on monistic approaches to embodiment and are framed in terms of

a disruption and blurring of bodily boundaries, and constant states of bodily flow and becoming (Irigaray, 1995; Potts, 2002; Young, 2005).

Bodies have been situated within poststructuralist theories as sites of power, regulation and resistance (Foucault, 1963, 1984). In illustrating his theory of knowledge and power, Foucault turned his attention to the body and sexuality as a site for the struggle of cultural meaning (Foucault, 1984; Mills, 2003). In his analysis of sexuality, Foucault demonstrates the way in which the proliferation of knowledge about sex and sexuality has produced structures which police the way in which we subjectively act and make sense of sexuality through discourse. He argues that the production of discourses of sex, simultaneously increase the power and regulation of sexuality (Foucault, 1984). The body is simultaneously the object of cultural discourses about the body and sexuality, but also the subject through which discursive positions are taken up and resisted through embodied practices.

Butler took up Foucault's theories relating to discourse, power and the body and argued that bodily practices produce femininity and heterosexuality (Butler, 1990, 1993). Also drawing on Lacanian psychoanalysis, for Butler, gender is produced as performativity, an organised set of culturally symbolic and discursive practices (Butler, 1990, 1993). In line with poststructuralist approaches to the body, for Butler, there is no essential 'natural' sex, other than that which is performatively brought into being through language and discourse as acts of subjectivity. Embodied actions are discursive productions, where gender is signified through the repetition of particular social acts that are regulated by cultural imperatives. For Butler, bodily movement and

practices signify one's subjectivity within the social order. This subjectivity is not categorically stable or safe, but fragile. Subjects create an illusion of continuity and stability by repetitively practicing embodied gendered acts over time. As such, embodied identities are based on a fiction that is open to threat from subject positions situated outside social norms and 'abject' within the symbolic social order. This means that identities, such as hetero-femininity, are not essential qualities of the body, but produced through discourse and embodied practices, repetitively performed over time, to create the illusion of such characteristics as 'innate' and 'natural' properties of the body.

#### Poststructuralist analyses of embodiment and subjectivity.

Researchers interested in sexuality and gender have used poststructuralist theories to analyse the ways that cultural contexts shape the bounds and possibilities of embodied subjectivities. Potts' (2002) work on heterosexuality and heterosex is helpful here in understanding particular discourses of sexuality, informed by sexology and medicine, that are taken up by individuals to inform experiences of sexuality and heterosex. Adopting an 'anti-essentialist' approach, Potts critiques mainstream sexology and medical approaches to sexuality that assert there is a unique, true and essential self that can be discovered and experienced through certain particular sexual practices. From a poststructuralist position, collective and institutional constructions of heterosex are important to understanding subjective experiences of sexuality and embodiment. Such a position identifies cultural imperatives as they relate to, and shape, sexual subjectivity and embodied sexual practices (e.g. McPhillips et al., 2001). In her analysis, Potts identifies

biological/reproductive, coital and orgasm imperatives operating as dominant cultural meanings that shape the 'nature' of heterosex. Potts then explores the way these discourses are used by men and women to describe meanings of sexual activity, and the implications for the social structures through which heterosex is produced. Further to the use of cultural imperatives, the dominant discourses within participant accounts of heterosexuality were constructed as binary opposites, including presence/absence, body/mind ('mind' included psychological and emotional components of sexuality), and inner/outer. Her analysis suggests that heterosexual experiences that are constructed as more connected with the 'truth' of self than others are those that involve the successful completion of sex (orgasm) through coitus, reflecting a hierarchy which privileges coital sex over other sexual practices (Jackson, 1995). As such, cultural imperatives, such as the coital imperative (Gavey, McPhillips, & Braun, 1999), shape the possibilities and limitations for meanings and practices that men and women construct around heterosexuality.

Gavey (2005) follows a similar approach to sexuality when exploring how normative cultural discourses inform the conditions of embodied sexual practices, opening up the complexities at play in heterosex to examine the subtle negotiation of consent, and the effective production and regulation of women's sexual desire. In her analysis, Gavey draws particularly on the have/hold discourse and the male sex drive discourse (Hollway, 1984), and role of these discourses within the 'heterosexual matrix' (Butler, 1990) to explain participants accounts of their sexual experiences. The have/hold, or Madonna/whore discourse, originally articulated by Hollway (1984), has been

demonstrated within a number of studies that have analysed experiences of heterosexuality. The discourse refers to the differentiating of women based on their sexual availability to men and the identities and moral consequences that accompany this for women. Women who are positioned as sexually active, desiring and available to men, risk being labelled morally defective as a 'slut', or a 'whore' (Ussher, 1997a), while women who are positioned as more sexually passive and less available to men, are deemed morally intact and suitable for the role of motherhood (Lees, 1993). The male sex drive discourse (Hollway, 1984) refers to the pervasive cultural discourse that men possess not only a stronger sex drive than women, but that this drive is an essential biological drive of the male body, which means that men are always ready and available for sex. As Gavey (2005) demonstrates in her analysis of interview material of women discussing sexual experiences, that both of these discourses effectively regulate both masculinities and femininities within heterosexual encounters, limiting choices and sexual desire within the bounds of culturally created meanings. These discourses actively produce the social conditions that shape the expectations placed on women in relation to sex, their obligations to 'give' men sex, and the consequences for their positioning as certain 'kinds' of women based on their sexual practices.

Gavey (2005) acknowledges that the 'heterosexual matrix' (Butler, 1990) is by no means simple and the processes by which gender and sexuality are produced in these contexts are complex and contradictory. The example of women giving their partners sex as a loving choice is given as an act indicating the complexity of subjectivity, although the potential restrictions on

the types of gifts that can be given around this is also acknowledged. In this way, acts of 'true' agency are difficult to establish as the bounds and possibilities, including those of resistance, are essentially culturally defined. Through this analysis, Gavey demonstrates the manner in which women's bodies are effectively socially produced and that our understandings and perceptions of our embodied experiences are structured within our cultural context.

#### Critique of poststructuralist discursive approaches.

Poststructuralist discursive approaches to subjectivity have been criticised as simplifying subjectivity and embodiment to particular discursive positions, termed a form of 'discourse reductionism' (Parker, 1997). This criticism has come from researchers who place more emphasis on the extradiscursive materiality of the body (Cromby, 2005; Ussher, 1997b; Yardley, 1997), and intrapsychic dynamics (Frosh, Phoenix, & Pattman, 2003; Hollway, 2006; Parker, 1997; Walkerdine, 1997), as contributing to the production of subjectivity.

Some poststructuralist approaches have addressed this critique by taking up psychoanalytic models of subjectivity to articulate how the inner psyche operates in relation to the social world (Hollway, 2006). As discussed earlier, discourses provide competing and conflicting subject positions for subjects to make sense of their 'selves' in relation to socio-cultural contexts. Proponents of psychosocial analyses, who employ psychoanalytic principles in their research, suggest that psychoanalysis is able to account for the

"explanatory gap" left open by poststructuralist discursive approaches to subjectivity, providing explanations of agency that include intrapsychic notions of investment and motivation in subject positioning (Frosh et al., 2003). In other words, psychoanalytic theories and principles can account for the question of why individuals adopt particular subject positions over others. In such approaches, more emphasis has been place on the 'inner life' of the individual, the role of the unconscious, and personal and social histories in contributing to subjectivity (Hollway & Jefferson, 2005).

Other approaches have taken a material-discursive and material-discursive-intrapsychic theoretical approach, often underpinned by a critical realist epistemology. These approaches seek to emphasise the extra-discursive materiality of the body and intrapsychic experiences by advocating for a position that legitimises intrapsychic experience as 'real', including psychological distress and emotion (Lafrance, 2009; Stoppard, 2000; Ussher, 2011; Yardley, 1997), while also acknowledging the role the material body plays in shaping the availability and limitation of particular subject positions. The interrelatedness of all of these aspects of embodied experiences contribute to the production of subjectivity, and can facilitate and impede particular intrapsychic experiences (Ussher & Perz, 2013; Ussher, Perz, & Mooney-Somers, 2007).

In answer to criticisms of discourse reductionism, particularly those directed by psychoanalytic and psychosocial approaches, proponents of poststructuralist discursive research argue that there are instances of discursive research where subjects have been produced as 'static' or 'fixed' within

subject positions (Gavey, 2002), which may have contributed to such criticisms. However, not all discursive research is produced with such simplicity (Wetherell, 2007). There are potentially more 'complicated' accounts of discursive subjectivity that could be produced by researchers, which account for fluidity, tension and contradiction within and across subjectivities, that may address some of the current criticisms of this approach (Gavey, 2002). Further, some critiques from psychoanalysis have influenced some discursive researchers to pay more attention to what is not said, as well as what is not said in participant accounts (Billig, 2006). In the following sections I will firstly review psychoanalytic and psychosocial approaches to subjectivity and embodiment, and then approaches that stress the materiality of the body through material-discursive, material-discursive-intrapsychic, and critical realist approaches.

# Psychoanalysis and Psychosocial Approaches to Embodiment and Subjectivity

Psychosocial approaches to research developed as a criticism of the overemphasis of the social to the exclusion of the psychic within critical psychology research. The aim of these perspectives is to incorporate both the psychic and social by employing psychoanalytic approaches to subjectivity. The main tenant of this perspective is that which is social is also psychic and vice versa. A psychosocial approach acknowledges materiality within social spheres of life, including the body in some senses (e.g. the 'maternal body', Hollway, 2006) and economic and social conditions (Layton, 2004; Walkerdine, 1997). Hollway (2004) refers to this approach as critical realist

psychosocial. There are arguments within these approaches concerning the relationship between the social and the psyche, with some theorists arguing for a stronger collapse of these concepts (Frosh & Baraitser, 2008), allowing for more emphasis on the cultural shaping of subjectivity (Burman, 2008; Parker, 2005a). Others argue that it is important to retain some sense of distinction between that which is 'outside' and 'inside' so that the 'psychic' is not completely absorbed by the 'social' (Jefferson, 2008), acknowledging a qualitative difference in the production of subjectivity between the two (Hoggett, 2008b). Further, Hollway (2008) argues that to split either position in to exclusive opposites is not helpful and that it is more beneficial to engage with the tensions that these positions create in application to research. As such, psychosocial theorists conduct a critique of discursive accounts of subjectivity in critical psychology and argue that subjectivity is not only produced in social interaction, but also through human development, and intrapsychic processes and emotions, including the unconscious.

Poststructuralist theorists have a history of drawing on psychoanalytic theory to make sense of the processes and relationships between the intrapsychic and the discursive (Hollway, 1989; Malson, 1998; Parker, 1992, 2011; Walkerdine, 1997; Walkerdine, Lucey, & Melody, 2002). In particular, psychoanalytic theory has been used to describe the way in which culture, as enacted in language, shapes intrapsychic experience (Malson, 1998).

Poststructuralist theory has historically drawn on Lacan and his incorporation of culture, through language, within his psychoanalytic theory (Sarup, 1993), and to theorise the limits of subjectivity beyond a "sum total" of discourse

positions over the life course (Henriques et al., 1984, p. 204). However, Lacan's psychoanalysis has been criticised by other factions of psychoanalysis for overemphasising the fragmentation of self to the exclusion of affect and cohesion which allows connection with Others (e.g. Layton, 1998). Object relations and relational psychoanalysts provide models of 'self' that are formed in relation to the other and take into account affect, the impact of trauma and relationships. Such approaches have important implications for understanding the agency of the subject, and methodological implications for conducting research, which will be discussed later in the chapter. First, the main theorists and applications of psychoanalysis and psychosocial studies will be reviewed. The theorists discussed in the following section provide accounts of subjectivity, which allow for change and fluidity within the psyche as it interacts with social contexts.

#### Lacanian psychoanalysis.

Lacan's psychoanalytic theory is written as a critique and development of Freud's psychoanalytic theory (Mitchell, 1982). Lacan took many of the concepts described by Freud and conceptualised them as symbolic within a linguistic framework, and rather than temporally located, he treated these processes as constant, dynamic acts of subjectivity (Bowie, 1991). For Lacan, all of our awareness (consciousness) is experienced through language and therefore, cannot be conceptualised separate from language. The unconscious also resembles language and is the site meanings that are repressed. Lacan also made use of Saussure's linguistic theory of the 'sign' (1974), and his conceptualisation of the 'signifier' and the 'signified' to support his

psychoanalytic theory (Bowie, 1991; Lacan, 1966). Developing the work of Saussure for the purposes of his own theory, Lacan inverted the relationship between the signifier and the signified, privileging the signifier as an act of subjectivity, which creates meaning. There is a constant flow between meaning (consciousness) and the disruption of meaning (unconscious). The important distinctions which Lacan made provide a theory that is helpful for contributing insight into the relationship between 'inside' and 'outside' worlds, the 'nature' of sexuality and desire, and representations of identity (Rose, 1982).

For Lacan, language is inherently structured according to the symbolic order, which is represented by the phallus, described through the castration and Oedipus complexes (Lacan, 1966; Rose, 1982). In these processes, both boys and girls begin by desiring the mother. As both become aware of the phallus, boys experience castration anxiety in their identification with the phallus as its presence also raises the possibility of its loss as punishment for desiring the mother. Girls realise their 'lack' of the phallus and attribute this as a symbol of being unable to fulfil their sexual desire. These feelings are resolved in the Oedipus complex whereby the girl and boy identify with the same sex parent, desiring the opposite sex parent. For girls this means identifying with the mother, who is perceived as also 'lacking' the phallus, and desiring the father. Boys identify with the father, who is also in possession of the phallus, and desire the mother. Lacan uses this model to make an important point: That the entering of the symbolic order (consciousness) comes about through an act of subjectivity, the symbolic resolution of the

castration and Oedipus complexes (Frosh et al., 2003). Through the process of 'awareness' one becomes located as 'gendered' and 'sexual' within the symbolic order (Weedon, 1997). These processes are symbolic for Lacan and are indicative of processes of desire and unconscious and the constant risk of disruption of identity by the unconscious (Lacan, 1966). Further, feminine identities are perceived in terms of 'lack', symbolic of the social order in which the phallus is more socially valued (Malson, 1998).

Lacan's psychoanalytic theory made use of Freud's mirror phase to articulate ideas of identity and representation (Bowie, 1991; Lacan, 1966). For Freud, this phase of development follows the infant stage of development where the infant identifies fully and completely with the mother. In the mirror phase the infant is able to look into the mirror and recognise one's self as an individual for the first time. Lacan again treats this process as a metaphor, removing it from its temporal location in Freud's theory of development. For Lacan, the mirror is conceptualised as a form of reflection of an image of one's self that can take the form of other people. The mirror allows a representation of the self in which one recognises 'I' in relation to other people and objects in the world within that image. By recognising 'I', individuals simultaneously identify with and position themselves in location to 'Other', locating themselves within a context of meaning and all that is not 'I'. The reflections seen in the mirror are not accurate versions of the 'truth' or 'reality', but rather unstable representations that are always in some sense fictional and open to the possibility of misinterpretation (Sarup, 1993). For Lacan, this is an ongoing dynamic process of continual identification and reidentification (Lacan, 1966). As such, there is a constant fiction present in gender and sexuality identity, in that the psyche is always fragmented, disrupted and negotiating tension (Lacan, 1966), a theorisation of the subject that has influenced discursive poststructuralist approaches to subjectivity (Weedon, 1997).

There have been strong criticisms directed at the use of Lacan's theories by feminist writers (Weedon, 1997). These criticisms have included, the universality of his model of the unconscious and a lack of location within historical context, and the normalising of heterosexuality and reinforcement of privileged (hegemonic) femininity and masculinity (Weedon, 1997). Grosz (1990) addresses this critique by arguing that this symbolic order is a description of patriarchy within the symbolic order rather than an inherent aspect of gender difference. Mitchell and Rose (1982) argue that these notions have been misunderstood and that these concepts rather than being treated as innate and assumed, are to be understood as positioning sexual identity as problematic and as a source of constant development. The aim of psychoanalysis, from this perspective, is to expose the fraud of the symbolic order represented by the phallus.

#### Object relations theory and relational perspectives.

Object relations theory refers to a school of psychoanalytic thought that developed through conceptualisations of an internal psychic world of 'objects' that are both real and imagined, conscious and unconscious, external and internal (Mitchell, 1986). 'Objects' refer to other people, ideas and values

(Hollway, 2006). The original advocates of this type of psychoanalysis (Klein, Fairbairn, Winnicott) challenged Freud's work by asserting that the psyche is fundamentally relational rather than driven by an irrational unconscious sexual drive (Hoggett, 2008a). For object relations theorists, the psyche is formed in relation to an object, or Other, the first of whom is the mother in the preoedipal infantile stage of development. Important in the formation of the psyche, even at the earliest stages of development, is the recognition of what is, and is not, 'me'. The process through which this happens involves the internalisation of object representations, the act of which brings about the division, or splitting of the psyche. This process has often been treated a form of psychic maturation through which individuation from the primary relationships occurs (Segal, 1978). Subsequent relational perspectives have emphasised the drive to connection and relationship with the subjective 'Other' (Layton, 2008), rather than what have been argued as masculine notions of psychic development through particular notions of 'independence' (Benjamin, 1988).

For object relations theorists, the representations within the psyche are 'ruled' by internal processes of splitting, and defence mechanisms (Mitchell, 1986). This has led to particular attention being given to experiences of psychic threat, anxiety, shame, and guilt, as these experiences are proposed as being linked to the particular function of an object and its relationship to the psyche and psychic development. For Klein (1952) splitting occurs in the internal representation of an object whereby the subject as a defence mechanism, introjects that which is protective, and projects that which is a

threat to the psyche. Klein's theory blurs the boundaries between self and other through the introjection of aspects of the representation of Other, and projection of parts of self onto Other. She uses the notions of the "paranoid schizoid" to describe a subject's position whereby too much splitting, while self protective, can result in too significant a division of 'self', impairing development through emotional avoidance. While a "depressive" and more 'healthy' position is one where a subject is able to recognise both the good and bad in an object and sit with the tension and discomfort of this experience (Klein, 1946). The implications for Klein's work create a picture of subjectivity which have important implications for the complexity of 'self', particularly when experiences of suffering are involved. Although weary of judgements of psychic 'health', and by implication, pathology, Klein's work contributes to notions of coping mechanisms. Klein's work around anxiety has also been used to explore interactions within social life and cultural structures including racism (e.g. Lowe, 2008; Tan, 1993) and social organisation (e.g. Lucey, Melody, & Walkerdine, 2003).

Relational perspectives of psychoanalytic thought extended object relations theories by acknowledging the Other 'object' as subject, capable of it's own subjectivity that cannot be reduced to the internal representations of one's psyche (Benjamin, 1995). The term inter-subjectivity is used to conceptualise the intersubjective space between two subjects, as something separate from both subjects, and which also contributes to the make-up of the psyche for both subjects. Inter-subjectivity, therefore, disrupts the assumed psychic boundaries between people through subjective acts such as empathy

and shared feelings (Hollway, 2006). As a result, relational psychoanalysts are particularly interested in processes of unconscious transference and counter-transference, within both clinical and research settings (Benjamin, 1995). Conceptualising the nature of the split and division of self, as an act of subjectivity which is driven either by the search for identity (cohesive self), or as a drive to form relational bonds with an Other (Layton, 2008). Maturation and relational approaches to the psyche are not proposed as mutually exclusive but consistent with models of the psyche as embedded with tension and contradictions (Benjamin, 1995).

Relational perspectives have been applied to rework psychoanalytic models of gender and sexual subjectivity (Benjamin, 1990, 1995; Layton, 1998, 2008). These models have often referenced poststructuralist notions of gender. In her reconfiguration of the Oedipus complex, Benjamin (1990) emphasises the emotional and sexual subjectivity in both sexes and a revaluing of the maternal as creating the capacity for greater emotional development and more integrated experience of the psyche. This enables subjects to recognise and connect with the Other across difference. For Benjamin, to make connection and recognise the subjective Other is the underlying unconscious drive of the psyche. Through this process, the subject has the opportunity to experience a unitary self (Frosh et al., 2003).

Psychoanalytic and psychosocial approaches of embodiment and subjectivity.

In the interest of exploring issues of femininity, embodiment, and how symbolism and intrapsychic dynamics may contribute to subjectivity, Malson's (1998) work around anorexia nervosa, embodiment and femininity can provide insight for this review. In addition to reviewing a range of cultural discourses and psychoanalytic approaches to understanding femininity, embodiment and anorexia nervosa, Malson also interviewed women about their experiences and understandings of anorexia. A feminist poststructuralist approach to discourse analysis was employed, as well as Lacanian psychoanalytic theory to interpret cultural dynamics contributing to the production of subjectivity for the women. Malson's analysis creates a complex picture of the anorexic body as a contested site of symbolic meanings, cultural discourses, and multiple, fragmented, and dynamic subjectivities. The anorexic body is both the site of the cultural object and vehicle through which the women exercise their agency, constructing subjectivities that signify (lacking) romantic feminine, subversive 'boyish', and a rejection of the vulnerable and biologically liable sexual feminine body. Further, the women adopted a discourse of Cartesian dualism to construct the mind as separate and in control of the thin body, avoiding signifiers of feminine excess through the thin body, and producing an ideal (phallic) self that transcended the (female) body. As such, through the anorexic body the women signified both a selfproduction and self-destruction of their (feminine) selves.

#### Critique of psychoanalytic and psychosocial approaches

Psychosocial and psychoanalytically influenced approaches to critical psychology have been criticised, often by more discursively focused researchers, for a number of reasons. Firstly, psychoanalytic models of subjectivity, while also theorising the subject as dynamic and changing, also suggest universal qualities are present in the inner life of individuals, such as conflict, anxiety, and particularly within studies drawing on object relations theory and relational psychoanalysis, the notion of the 'defended subject' (Frosh et al., 2003; Walkerdine, 1997; Walkerdine et al., 2002). Such claims can be unsettling, especially for those committed to the idea of fragmented, non-unitary subjectivity that is dependent on social context (e.g. Gavey, 2002).

Secondly, by using theories that draw on universal principles to determine underlying intrapsychic dynamics beneath the surface of discursive actions, it can be seen that researchers (as subjects) are positioned as having access to knowledge about the 'nature' of the unconscious in another, and the role of these dynamics in producing subjectivity that the participant themselves may not have (Gavey, 2002). At times, such analytical actions can appear as a fairly large step beyond the text and into a subject's developmental past and inner life, particularly analysing and problematizing the role of parental relationships, such as the suggestion by Hollway and Jefferson that "Vince" idealises his boss in a way "that has the flavour of an ideal father figure" to make up for the absence of a father figure in his life (2005, p. 159). Criticisms about critical researchers going outside accounts produced by participants have also been directed at discursive feminist poststructuralist

research as going beyond that which may 'directly observable' in participants' talk, and that participants may or may not be 'intending' to produce the meanings in their talk that they are attributed through analysis (Schegloff, 1997). Such criticisms have been answered in terms of arguing that analyses must address the extent of the social world that participants orient their talk towards, including shared social meanings (Weatherall, 2000). Both discursive and psychoanalytically informed researchers have also addressed aspects of these criticisms by focussing both on the detail produced in the participant's talk, emphasising the meaning-making produced by participants (Saville Young & Frosh, 2009). In terms of psychoanalytically influenced work, this is particularly evident in those approaches informed by Lacanian psychoanalysis, in which subjectivity is a creative, symbolically entwined act, rather than the discovery of 'deep' intrapsychic dynamics (Saville Young & Frosh, 2009).

Thirdly, concepts of investment, motivation and unconscious dynamics within psychoanalysis and psychosocial research have implications for the agency of the subject. Psychoanalytically informed research purports that unconscious dynamics contribute to the production of subjectivity. And, that taking into account personal subjectivity is equally important as accounting for social subjectivity (Frosh et al., 2003). It has been argued that critical research needs to acknowledge the 'choices' made by subjects within the realm of personal subjectivity, and that, while these are not separate to the dynamics of social contexts, they are produced through unconscious dynamics and biographical influences (Hollway & Jefferson, 2005). Apart from the criticism of the lack of definition of 'unconscious dynamics' (Wetherell, 2005), a

common debate across different schools of psychoanalysis (Hollway & Jefferson, 2005), such a theorisation of subjectivity can result in a position where the psyche, and specifically unconscious dynamics, are privileged as determining subjectivity, rather than socio-cultural context (Wetherell, 2007). Such an idea may also have implications for positioning of responsibility in the production of oppression and role of socio-political change in resisting power, a criticism also taken up by some Lacanian influenced psychosocial researchers (Burman, 2008).

As a methodological implication, psychosocial research tends to rely more heavily on case studies and individual narratives (Hollway & Jefferson, 2000). These can be examples of patterns that exist in a data set, or 'extreme cases', and are interpreted in relation to theory. Hollway and Jefferson (2005) argue that such methods are important to the empirical research of the psychosocial subject as this allows researchers to privilege the biographical events in an individual's life as contributing to their intrapsychic state, dynamics contributing to investment in particular subject positions, and to test the theoretical perspectives from which interpretations are drawn. This contrasts with poststructuralist discursive work that often works with observations of patterns made across the data sets, as well as variation within particular data sets (Potter & Wetherell, 1987). Such an approach allows this research to analyse what is common and different to particular accounts overall. Discursive research places more emphasis on the social, by interpreting patterns and variability in relation to broader socio-cultural discourses. This has implications for subjectivity, as discursive analyses will

highlight how discursive resources function to facilitate and limit possibilities for subjectivity, saying more about the functions of those discourses and discursive dynamics than the inner life of an individual (e.g. Gavey, 2002) which avoids any notions of pathologising individuals.

A final and important criticism in the context of this study is the extent to which the materiality of the body is acknowledged in psychoanalytic and psychosocial accounts of subjectivity. While some of the examples of research and theories reviewed drew on the role of the body in psychic developmental (Hollway, 2006), and in imaginary and symbolic senses (Grace, 2010), much of the theory and research did not emphasise the material, extra-discursive aspects of embodiment as shaping the possibilities and limitations of subjectivity, discursive practice and intrapsychic experience. This has important implications when dealing with subject matter where there is a presence of a particular bodily condition, such as cancer, that can change the functioning and appearance of the body through the progression of disease and subsequent treatments.

## Material-Discursive and Material-Discursive-Intrapsychic Approaches to Embodiment and Subjectivity

Material-discursive-intrapsychic theoretical approaches (Ussher, 2000) developed from a material-discursive approach, which was a response to a call for greater emphasis on the extra-discursive in discursive and constructionist psychology (Cromby & Nightingale, 1999; Ussher, 1997b; Yardley, 1997). Advocates of a material-discursive position have argued that not all is

reducible to the 'bounds and possibilities' of discourse (Cromby & Nightingale, 1999; Hunter & O'Dea, 1997), and that the discursive cannot be conceptualised as separate from the material (Squire, 1997). Materialdiscursive approaches have included the production of research that critiques institutional and 'common sense' forms of knowledge, while also emphasising the material conditions and lived experiences of people affected by such conditions (Swann, 1997; Ussher, 1996). Proponents of this approach have argued that incorporating these aspects of experience so they are not reduced, but engaged with in a way that acknowledges the interrelatedness of both aspects, opens up discussion about the functioning and implications of the relationship between the material and discursive (Ussher, 1997b). As such, material-discursive approaches have been used in the areas of health and illness (Yardley, 1997), sexuality (Bellamy, Gott, Hinchliff, & Nicolson, 2011; Hinchliff, Gott, & Wylie, 2009), reproduction (Ussher, 2008b, 1997b), depression (Lafrance, 2009; Lafrance & Stoppard, 2006), and embodied constructions of identity (Johnson, 2007). Critical realism is often used as an epistemological framework from which to ground material-discursive and material-discursive-intrapsychic research (Ussher, 2008b).

In regards to embodiment, material-discursive approaches, like other discursive approaches reviewed, have been used to collapse dualist approaches to the body, including mind-body (Yardley, 1999) and subject-object (Reuter, 2002). A material-discursive framework has been used by studies that have explored the materiality of the body, integrating these experiences, actions and events with discursive meanings associated with the body, particularly those

where body changes have disrupted the ability or willingness of subjects to identify with 'normal' cultural discourses or imperatives (Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004). In the context of critical health research, this means that studies that have incorporated a material-discursive position have been used to integrate participant subjective meanings of health and illness, along with the 'actual' occurrence of illness and the impact this has on bodies and lived experiences (Ussher, 1997b). This conceptualisation of 'materiality' has extended beyond emphasising the materiality of the body to include the legitimising of experience, including intrapsychic experiences. While the intrapsychic is not referred to as a specific dimension in this version of the theoretical model, through the use of participant experiences as legitimate sources of knowledge, attention has been given to aspects of intrapsychic of experience as 'real', including emotional regulation, and psychological distress and wellbeing (Lafrance, 2009; Lafrance & Stoppard, 2006).

In an example of the use of a material-discursive approach, Lafrance (2009; Lafrance & Stoppard, 2006, 2007) adopted a material-discursive theoretical position in her analysis of women's accounts of recovery from depression. This study examined how women made sense of a depressive experience and their sense of 'selves' within this context. A material-discursive position was used to acknowledge the materiality of embodied experiences of depression, and the social, political and economic conditions that contribute to depression, while also legitimising the distress, pain and suffering caused by depressive experiences. By adopting this theoretical

approach, the study also acknowledged women's experiences of depression as occurring with particular cultural contexts. The study explored the way discourses of femininity were accounted for by the women in their narratives of depression, and subsequently negotiated in making sense of recovery, wellbeing and a transformation of self through these experiences. The cultural idealisation of the 'good woman' as a highly valued form of femininity, contributed to the cultural conditions in which the women experienced depression. The 'good woman' is a woman who puts the needs of others before her own, and is in control of her body and emotions, meaning that depressive experiences are often self-silenced and efforts to self-care to nurture recovery risked experiences of guilt, shame and feelings of inadequacy for the women (Lafrance, 2009). While the women tended to draw on individualised and de-politicised discourses of recovery, Lafrance (2009) found that women resisted such discourses of femininity in their accounts of recovery, to create narratives of empowerment and personal transformation. Through her analysis Lafrance (2009) suggest that discourses of femininity can limit the availability of discursive resources and subjectivities that can be taken up by women to assist in their recovery and transformation from depressive experiences.

In another example, a qualitative interview study conducted by Hinchliff, Gott and Wylie (2009) explored accounts of heterosexual women who had experienced the loss of sexual desire. The authors took a material discursive theoretical position to integrate the material-embodied and subjective aspects of experience. The theoretical position was also adopted to

legitimise the experiences of the women in the study as a source of knowledge, including the impact of sexual desire loss on the women's lives, and the consequences for the way in which the women subsequently viewed and experienced their 'selves', bodies, partner relationships, and psychological distress. These experiences were made sense of in the context of cultural constructions of feminine sexual 'norms', with the women talking about their experiences as not being 'normal'. The loss of sexual desire subsequently had implications for the women taking up subject positions that were 'othering' of their selves, and positioned themselves as abnormal and odd. The women also spoke of the loss of sexual connection within their relationships, being unable to fulfil sexual roles and expectations within their relationships, and a change in perceptions of body attractiveness, which often had a detrimental effect on emotional wellbeing. Being outside the sexual 'norms' of womanhood contributed to a sense of isolation and difficulty for the women due to the absence of the experience of sexual desire loss in cultural discourses of heterosexual sex and relationships.

As noted above, a material-discursive-intrapsychic theoretical framework was developed from a material-discursive theoretical approach, as a response to the call for further emphasis and acknowledgement of intrapsychic aspects of experience (Ussher, 2000). Material-discursive-intrapsychic approaches to research provide a theoretical framework to incorporate each of these 'levels' of experience, while also viewing their interrelatedness as producing possibilities and restraints for subjectivity. The 'intrapsychic' includes affective states, emotions, psychic dynamics, conflicts,

anxiety, defences, coping mechanisms, and the intrapsychic aspects of subjectivity itself, similar to a sense of 'self' (Ussher, 2000). Not one theoretical approach is prescribed for addressing the intrapsychic, but rather, the framework emphasises the importance of accounting for the interrelatedness of these aspects of experience and emphasising the material and intrapsychic as extra-discursive, while also conceptualising these experiences as mediated through culture (Ussher, 2000). As such, the intrapsychic aspects of subjectivity can be analysed, including how particular internalisations of cultural imperatives, ideals and norms are related to particular emotional and affective states, including psychological wellbeing and distress (Ussher, 2008a). As noted previously, some of these aspects of experience have been addressed implicitly, through many studies that have employed a material-discursive position (e.g. Lafrance, 2009; Lafrance & Stoppard, 2007). However, the aim of employing a material-discursiveintrapsychic approach is to give further emphasis to such dynamics and experiences (Ussher, 2000). As such, a material-discursive-intrapsychic theoretical approach has been used to account for the subjectivity studies that have examined sexuality after cancer (Gilbert, Ussher, Perz, et al., 2013), premenstrual syndrome (Ussher et al., 2007), depression (Stoppard, 1998; Ussher, 2011), domestic violence (Nicolson, 2010), women with a diagnosis of borderline personality disorder who self-harm (Walker, 2009), women's maternal experiences (Winstanley, 2005), women's health interventions (Erskine et al., 2003), motorcyclist risk taking (Haigh, 2008), and the sexual desire of Catholic priests who have a history of molesting children (Winship, 2012).

#### An Epistemological Framework: Critical Realism

As noted above, critical realism has often been adopted to ground material-discursive and material-discursive-intrapsychic accounts of participant experiences (Ussher, 2000, 2008b). Critical realism is a philosophy of science developed by Bhaskar (2011), which collapses the dichotomy in the social sciences between realism and relativist discursive forms of knowledge (Parker, 1999). Critical realism's main proposition is that there is a world (materiality) that exists independently of our selves, but that our knowledge of this world is mediated by cultural processes and knowledge (Sayer, 2000). Realist approaches do not distinguish between ontology and epistemology treating both from a positivist perspective (Pujol & Montenegro, 1999). Similarly, constructionists have been criticised for treating both ontology and epistemology in terms of a relativist epistemology. Critical realism distinguishes between ontology and epistemology arguing for a realist approach to ontology and a relativist epistemology (Bhaskar & Lawson, 1998). In doing this, critical realism critiques positivist deductive reasoning (Bhaskar & Lawson, 1998), and is positioned broadly within constructionism in that it expands what is considered 'knowledge' within psychology to also include cultural knowledge and lay understandings of phenomena and experience (Sayer, 2000). At the same time, critical realism critiques relativist approaches of the construction of knowledge, arguing that there are limits and bounds on the production of our cultural and social experiences, including the materiality of economic and social conditions (Bhaskar, 2011).

Critical realism was introduced to the realism versus relativism debate as an alternative to both points of view (Parker, 1999). However, it has also been argued that critical realism articulates a position which relativists had always advocated in their approach to knowledge and reality (Speer, 2000). The implications of critical realism for research practice include an ability to embrace a range of different methodologies, including those drawing on cultural and lay knowledge, while at the same time arguing that these should be held in ongoing critique and acknowledged as producing different types of knowledge (Sayer, 2000; Williams, 2003).

## Critique of Material-Discursive and Material-Discursive-Intrapsychic Approaches.

Material-discursive theoretical frameworks have been critiqued for being reflective of the mind-body dualism that such an approach is attempting to collapse (Morgan, 2005). If one aspect of subjectivity is not collapsible to the other, or cannot be 'undone' by the other, it is possible that there is a 'nature' to the body. Some proponents of discursive poststructuralism have expressed discomfort with this idea due to a perceived similarity with more positivist 'essentialist' approaches to the body. However, some studies using a material-discursive and material-discursive-intrapsychic approach have examined how the material body can be experienced differently depending on the discursive meanings made of the body and embodied experiences. For example, renegotiating sexual practices after cancer where changes to the body due to cancer have prevented 'normative' coital heterosexual practices, to emphasise non-coital sexual practices (Ussher et al., 2013).

While both material-discursive and material-discursive-intrapsychic theoretical approaches differ from mainstream approaches to subjectivity through the emphasis on the discursive, and from some discursive approaches through their emphasis on the extra-discursive, there are different variations in the way that the framework has been employed within research (Stoppard, 2010; Ussher, 1997b). A material-discursive-intrapsychic approach as a theoretical framework has been criticised for not articulating how each aspect of experience is related, beyond saying that they are interrelated (Stoppard, 2010), and in particular, for not saying exactly how the intrapsychic is incorporated into the theoretical framework. Addressing this the issue, Grace (2010) has argued for incorporating a Lacanian approach to subjectivity when the elements of the framework are theorised beyond 'interrelation' and placed within the realm of the culturally symbolic, a move that is arguably already present in some respects in material-discursive-intrapsychic approaches, and similar to other discursive and Lacanian approaches covered in this review. Importantly, Grace (2010) argues for the contribution of Lacan's idea of the imaginary (intrapsychic), as structured by fantasies of the unitary subject, in which the body is (falsely) perceived as whole and unified, forming a selfboundary. It could also be argued that due to the lack of prescription of how the intrapsychic should be addressed in material-discursive-intrapsychic approaches, there is the possibility of going further into intrapsychic dynamics, such as those articulated by psychoanalytic notions of anxiety, conflict, defence mechanisms and splitting, as well as cognitive approaches such as coping mechanisms (Ussher, 2000). Equally, consistent with a critical realist epistemology, interpretive frameworks can be employed in a manner

consistent with the aim of the particular research project, and how intrapsychic experiences are discussed, implied, or repressed in particular participant accounts. Such an approach could be considered a reflexive methodology, a subjective approach to data analysis similarly advocated by other poststructuralist forms of discourse (Gavey, 2011) and psychoanalytically influenced analysis (Hollway & Jefferson, 2000).

## Application of Material-Discursive-Intrapsychic Framework to the Current Study

A material-discursive-intrapsychic theoretical framework, within a critical realist epistemology, was adopted for the current study. Due to the extra-discursive nature of cancer, it was decided that a theoretical approach that acknowledged the materiality of the body in shaping the possibilities for embodied sexual subjectivity was important. In addition, an emphasis on the intrapsychic dynamics and experiences of participants was also considered an important indication of how participants may be experiencing embodied sexual changes, and how they were experiencing their sense of 'self' and relationships through their cancer experiences. Further, as noted above, the discursive construction of heterosex, femininity and sexual subjectivity needs to be acknowledged to account for how women construct and experience their subjectivities. The application of a critical realist epistemology for this study has strengths for conceptualising illness as event with material significance for the body, while also positioning such an event as occurring within a sociocultural context that shapes constructions and experiences of illness (Williams, 2003). Critical realist arguments have been used by theorists advocating for a

greater emphasis on subjectivities and 'selves' within constructionist research as involving 'actual' bodily experiences with the cultural meanings that we give to these experiences (Cromby, 2005). Such a theoretical approach allows criticism of biological approaches and the cultural assumptions that have led to the production of knowledge in the areas of women's health and sexuality (Ussher, 1996, 2008b), while also acknowledging the contribution of material body changes and physiology that can contribute to sexual problems following cancer, as discussed in the literature review (e.g. Jensen, 2007; Traa et al., 2012).

The application of a material-discursive-intrapsychic theoretical approach stresses the importance of the discursive aspects of gender, sexuality and the body, that are currently lacking in existing studies on women's experiences of sexuality after cancer as noted in the literature review (Chapter Two). A material-discursive-intrapsychic approach also positions the interview participants as legitimate sources of knowledge (Ussher, 2000), which is important in a study examining women's experiences of sexuality, an area still dominated by biomedical and gender-biased frameworks for understanding women's sexual experiences (Tiefer, 2002). The range of theoretical literature reviewed for this study indicates the complexity of subjectivity and the dynamics at play within material, discursive and intrapsychic aspects of experience, which even when conceptualised as 'interrelated', can have complex implications for subjects within social practice. As such the women's experiences of embodied sexual subjectivity will be explored through participant descriptions, with subjectivity

conceptualised as a material-discursive-intrapsychic construct. The theories reviewed have influenced the way that these dimensions of experience were 'read' in participant accounts, and the construction and presentation of the analysis. Such an approach included the theorising of discourse, dynamics of discourse and symbolism, multiple, changing and fragmented subjectivities, and focusing attention on what participants said, as well as possible meanings that were silenced during the accounts. I have tended to structure my analysis as primarily material-discursive with intrapsychic experiences read through participant descriptions of affect and other intrapsychic dynamics. As such, my efforts at interpretation of intrapsychic experience have largely been through the 'implications' of my analysis, that is the implications of women's embodied sexual subjectivity.

### **Chapter Four: Methodological Framework**

As noted in Chapter Three, the present study analysed women's experiences of embodied sexual subjectivity post-cancer, employing a material-discursive-intrapsychic framework (Ussher, 2000), within a critical realist epistemology (Bhaskar, 2011), drawing on a poststructuralist approach to conceptualising cultural context and subjectivity. The analysis for this study adopted a feminist poststructuralist approach to discourse analysis (Gavey, 1989). Poststructuralist approaches to discourse analysis have an established history within discursive psychology (Gavey, 1989; Henriques et al., 1984; Hollway, 1989; Parker, 1992; Potter & Wetherell, 1987), and have been used when researchers are interested in how cultural and socio-political contexts inform experiences and constructions of subjectivity (Burman & Parker, 1993). By employing a 'feminist' approach, this research is centred on the women's perspectives of their experiences (Griffin & Phoenix, 1994), and is interested in how particular gendered experiences and practices are shaped by social context and possibilities of change, both in the context of women's everyday lives, and broader social change (Brooks, 2007). The current chapter will firstly discuss the research design for this study, recruitment procedure for participants, and the sample of women who were interviewed. Secondly, the interview procedure, pilot interviews, interview questions, the 'nature' of the interview context, including the process of the co-constructed intersubjective interview, and the mode of communication when dealing with sensitive issues around intimate body changes, sex and sexuality, will be reviewed. Finally, the analytic strategy used in the study will be discussed, including the

approach to transcription, and the methodological approach to the discursive thematic analysis conducted.

### **Research Design**

The aim of this study was to examine women's experiences of sexual embodiment in the context of cancer, with the following questions used to direct the study: How do woman make sense of their body experiences and sexual selves in the context of cancer? How do women understand and experience their sexual relationships in the context of cancer? The study involved the analysis of transcripts from semi-structured interviews conducted with sixteen women who had a diagnosis of cancer. Participants were selectively sampled based on cancer type, age and relationship status, so that gendered experiences of sexual embodiment could be examined across these factors. Audio recorded face-to-face and telephone interviews were conducted with the sixteen women and all interviews were transcribed verbatim. A thematic discourse analysis was conducted, employing a feminist poststructuralist approach to discourse (Gavey, 1989), and drawing on thematic decomposition analysis (Stenner, 1993) in which the data was organised according to overall coherent 'themes' that accounted for the subject positions that the women adopted in their accounts. By employing this approach, the analysis was able to account for how social contexts shape the women's experiences and constructions of embodied sexual subjectivity postcancer.

### **Recruitment Procedure**

The current study is part of a larger Australian Research Council (ARC) funded project: 'Multiple perspectives on sexuality and intimacy post-cancer, leading to the development and evaluation of supportive interventions'. The ARC project included both men and women with cancer, and their partners. As part of the ARC project, participants were recruited through a range of support organisations, clinics and the media. Participants for this study were selected from the pool of women participants who took part in the ARC study and who indicated a willingness to be interviewed after first completing an initial questionnaire. The research protocol for the study received ethics approval from the UWS Human Research Ethics Committee (H6545).

Using demographic and open question information from the ARC study questionnaire, participants for this study were purposively sampled to include approximately equal numbers of women presenting with breast or gynaecological cancers, and other forms of cancers, in order to extend the findings of previous studies on sexuality that have tended to focus on women with breast and gynaecological cancers. Purposive sampling was also used to include women across a range of different age groups to account for experiences and constructions of ageing as they relate to the body, gender and sexuality within the sample. Finally, participants were selected to include women from different heterosexual relational contexts, including long-term relationships, 'dating' relationships, women who are single, and women whose relationships had ended due to cancer. By including women from different

relational contexts and focusing on heterosexual women, the study was able to take into account how different intersubjective contexts, as well as the way that heterosexual discourse may shape women's experiences of sexual embodiment after cancer. Heterosexual women were chosen in order to account for the role of hegemonic discourse as it relates to these women, which is currently unaccounted for in existing studies, as discussed in Chapter Two.

Potential participants were sent an information pack in the mail that included a written invitation to participate in the study, an information sheet outlining the nature of the study and ethical information, and a written consent form (See Appendix). If a reply had not already been received, I made followup telephone calls to participants two weeks after the invitation had been sent, to gauge their interest in participating in the interview. Seventeen women were initially invited to participate and 16 women consented to be interviewed. One woman did not respond to two follow-up phone calls, at which point I decided not to continue contact, given the sensitive nature of the study, so as to avoid the possibility of distress to the woman. The contacting of potential participants ceased when the criteria for purposive sampling had been filled, and no new concepts were identified in the interview texts, as guided by the research questions and theoretical perspective adopted (Devers & Frankel, 2000; Marshall, 1996). Following the interviews, all participants were given pseudonyms and any identifying information was excluded in the reporting of the analysis to protect confidentiality.

## **Participants**

The participants in this study were aged between 20 and 71 years of age (average age was 46 years of age), with half of the sample aged between 40 and 49. Fifteen women identified their ethnic background as Anglo Australian and one as Asian Australian (Lucy). Of the 16 women, six were diagnosed with breast cancer, four with gynaecological cancers (uterine, ovarian and cervical), two with lymphomas, one with thyroid cancer, one with leukaemia, one with anal cancer, and one with colorectal cancer. Two women with a breast cancer diagnosis received subsequent diagnoses of throat cancer and lung cancer. One participant with uterine cancer was later diagnosed with breast cancer, one participant with anal cancer was subsequently diagnosed with thyroid cancer, and one participant with non-Hodgkin's lymphoma was subsequently diagnosed with skin cancer. The time since primary diagnosis at the time of the interview ranged from seven months to eleven years.

The stage at which cancer was diagnosed varied across the women from early to advanced cancers. However, no participant had been given a terminal diagnosis at the time of contact or interview. The main types of treatments that the women had received for their cancer varied across the sample, including surgery, chemotherapy, radiotherapy, and hormonal treatment. Participants with thyroid cancer received radioactive iodide treatment and a participant with non-Hodgkin's lymphoma received two stem cell transplants. Fifteen of the participants had finished the acute stages of treatment at the time of interview. One participant was recovering from an ileostomy reversal at the time of the interview and was yet to complete a final

course of chemotherapy. The six participants with breast cancer were all receiving hormonal treatment on an ongoing basis at the time of the interview.

Nine of the women in this study indicated on the questionnaire they were currently in a relationship with a male partner. At the time of the interviews, all of these nine participants were in the same relationship they had indicated on the initial questionnaire, with seven of those living with their partners. A further two participants were in heterosexual relationship, and not living with their partner. Seven participants were single, or without a regular partner, at the time of the completion of the questionnaire and interview. Of the seven participants who were not in a relationship at the time of the interview, two participants had had new sexual partners following cancer, including one who had an ongoing casual sexual relationship. Another two participants were no longer interested in having a sexual relationship and three were unsure of future relationship possibilities. All of these women indicated a salient heterosexual orientation in their accounts of past and possible future relationships, with the exception of Lucy, who said she had dated both men and women in the past within her interview. The relational context salient to Lucy's interview was the break up of a long-term relationship with a male partner due to cancer, which is discussed in her pen portrait.

#### **Pen Portraits**

Sofia was 47 years old and had been diagnosed with colorectal cancer seven months prior to the interview, although she said that her cancer was "quite low" so it was "more like rectal cancer". She had received surgery,

including an ileostomy, as well as chemotherapy and radiation treatment. At the time of the interview she was recovering from surgery to reverse her ileostomy and had a final round of chemotherapy to complete. Sofia had been with her partner for two years at the time of the interview, which she described as a "dating" relationship, with her and her partner living separately.

Gwyn was 47 years old and had been diagnosed with cervical cancer about two years prior to the interview. She had received surgery, chemotherapy and radiation treatment. Gwyn had been with her partner for 26 years and had four children, two of whom lived at home.

Robyn was 60 years old and had been diagnosed with endometrial cancer 11 years, and breast cancer two years prior to the interview. She received surgery for her endometrial cancer, and then additional surgery, radiation and chemotherapy treatments for her breast cancer. Robyn had been married at the time of her endometrial cancer, however her relationship broke up due to the sexual changes she experienced after her surgery. She was subsequently single during her experience of breast cancer.

Sonia was 49 years old and had been diagnosed with breast cancer more than two and a half years prior to the interview. She received a couple of operations, radiation and a year of chemotherapy treatment. Sonia decided to have a double mastectomy to remove both of her breasts to prevent the cancer from returning and decided not to have a reconstruction, in part, to allow any possible recurring cancers to be more easily detected without being obscured

by implants. Sonia was married to her husband of more than 24 years at the time of the interview and had two adult children.

Lucy was in her late forties and had been diagnosed with breast cancer about a year prior to the interview. She had received a number of operations in addition to chemotherapy and radiation treatments. Following her surgery, Lucy had problems with her mastectomy healing, which remained unhealed at the time of the interview. Lucy had been living with her male partner at the time of her cancer. However, her partner had an affair and broke up with her due to the sexual changes she had experienced and the uncertainty of her health status. She was currently single at the time of the interview.

Philippa was 50 years old and had been diagnosed with ovarian cancer nine months prior to the interview. She had received surgery and chemotherapy for her cancer, and had found out that she was at high genetic risk of breast cancer a few days prior to the interview. Philippa was taking part in a clinical trial to maintain her chemotherapy treatment, but did not know if she was taking an active pill or a placebo. She was single at the time of interview.

Laura was 41 years old and was diagnosed with breast cancer more than five years prior to the interview. Her breast cancer subsequently metastasised to her lungs. She received surgery, chemotherapy and radiation treatment for her breast cancer and chemotherapy for her metastasised cancer. Laura was taking ongoing hormonal treatment at the time at the interview that she reported was responsible for her severe vaginal dryness. She was living

with her partner of 20 years at the time of the interview, and had two young children.

Ellen was 62 years old and was diagnosed with endometrial cancer more than eight years prior to the interview. She had received surgery for her cancer. Ellen was single at the time of her cancer, meeting her partner after the conclusion of her treatment. Her questionnaire indicated that her partner had advanced prostate cancer at the time of the interview, which had affected his sexual desire. However, Ellen did not report any changes to her sexual functioning and reported her sexual relationship as highly satisfying. Further, her partner's experiences were not salient in her account. She was living with her partner, who she had been with for about eight years at the time of the interview.

Anna was 25 years old and had been diagnosed with Hodgkinson's lymphoma two years prior to the interview. She had surgery, chemotherapy and hormonal treatments for her cancer. Anna had gone through menopause following her treatment and had been talked to by specialists about the risk to her fertility and fertility options as part of her treatment. She was single at the time of her treatment and the interview.

Christine was 62 years old and had been diagnosed with breast cancer two years prior to the interview. Following her initial diagnosis she was also diagnosed with throat cancer. She received surgery and hormonal treatment for her breast cancer, and radiation treatment for her throat cancer. Christine elected to have a breast reconstruction following her mastectomy and also had

a breast augmentation to her remaining breast to create symmetry between her breasts. She was awaiting the reconstruction of her nipple to her reconstructed breast at the time of the interview. Her and her partner had been together over five years with periods of separation. Christine reported that her partner been pursuing other women while she was experiencing sexual problems due to cancer. They had not lived together.

Marie was 40 years old and had been diagnosed with breast cancer less than two years prior to the interview. Due to her genetic risk for breast and ovarian cancer, she had elected to have both breasts removed with reconstruction and also had her ovaries removed. In addition, she also had chemotherapy and hormonal treatment. Marie was living with her partner of 17 years at the time of the interview and had two young children.

Jackie was 53 years old and had been diagnosed with non-Hodgkin's lymphoma eight years prior to the interview. She had received three diagnoses of lymphoma, including one recurrence, and an additional skin cancer diagnosis. Jackie received a stem cell transplant twice with chemotherapy for her diagnoses of lymphoma, and surgery and radiation for her skin cancer. Her and her ex-partner had separated three months prior to her first diagnosis. She positioned her cancer and the sexual changes she experienced as having, in part, a positive impact, in that it created further distance between her and her ex-partner, saying that the relationship had been very stressful. Jackie subsequently reported enjoying being single.

Holly was 20 years old and had been diagnosed with acute myeloid leukaemia more than two years prior to the interview. She received chemotherapy for her cancer. Holly was in a relationship at the time of her cancer and lived with her partner after her cancer treatment. Holly said that her libido disappeared during this time and they did not have sex. Her and her partner's feelings towards each other changed during this time and they broke up, after which she felt her libido returning. She subsequently resumed sexual activity with new partners.

Joanna was 42 years old and had been diagnosed with anal cancer two years prior to the interview. Subsequent to her first diagnosis she was also diagnosed with thyroid cancer. Joanna received chemotherapy and radiation for her anal cancer, and surgery with radioactive iodine treatment for her thyroid cancer. She was living with her partner of 19 years and had three young children at the time of the interview.

June was 71 years old and diagnosed with breast cancer more than seven years prior to the interview. She received surgery, chemotherapy and was taking ongoing hormonal treatment at the time of the interview. June was living with her partner of 35 years at the time of interview.

Eva was 22 years old and diagnosed with thyroid cancer more than three years prior to the interview, which had subsequently recurred. She had received surgery and radioactive iodine treatment for both her initial diagnosis and recurrence of cancer. She was in remission at the time of the interview. Eva had a boyfriend that she had been seeing in high school when she was

initially diagnosed with cancer. They had not had sex at the time of the diagnosis and she broke up with him at the time so as not to burden the relationship. Eva had had a couple of sexual partners since her initial cancer diagnosis, and an ongoing casual sexual relationship with her high school boyfriend at the time of the interview.

#### **Interview Procedure**

Four participants lived within the Sydney Metropolitan area at the time of the interviews and were interviewed face-to-face. These participants were given a choice as to the location of the interview, whether on the University campus or in their homes. Three participants chose to be interviewed in their homes and one was interviewed at her place of work. Due to geographical restrictions, twelve participants who were outside the Sydney Metropolitan area were interviewed over the phone. The interviews lasted between 31 minutes and an hour and 40 minutes, with most interviews lasting around 60 minutes. Interviews were audio recorded and later transcribed verbatim.

The semi-structure interviews were conversational in nature (Kvale & Brinkmann, 2009). The wording and format of questions were used flexibly to suit the context of the particular participant. As the interviewer, I tried to avoid directive or close-ended responses, and used prompts to further open up descriptions of experience. As a culturally established form of interaction, participants (interviewers and interviewees) perform their particular roles according to the aims of an interview interaction (Heritage & Clayman, 2010). In awareness of a potential for rigidity in the structure of the interaction, I

prefaced the interviews by saying that they were conversational in nature, rather than a more formal question-answer format. I positioned the aim of the interviews upfront as being about trying to understand what had happened for the women in terms of their own experience with cancer, or their 'story', as an attempt on my part to disrupt any assumptions that participants had to wait for me to direct the interview as part of my role as the interviewer. Such positioning, also sought to emphasise the value of in-depth personal stories and accounts, and was part of a conscious attempt to position the participants upfront as holding the knowledge and expertise over their own experiences (Brooks, 2007).

#### Interview schedule.

The themes covered in the semi-structured interview for this study were designed to explore the research questions: how do woman make sense of their body experiences and sexual selves in the context of cancer? How do women understand and experience their sexual relationships in the context of cancer? The interviews were initiated with the question, "can you tell me about your cancer journey?" This question was designed to elicit narratives that formed the context for participants to talk about their embodied experiences and sexuality (Thomas-MacLean, 2004a). The second question asked participants about the changes they had noticed to their bodies over the course of their experience with cancer (if any) to allow participants to orientate towards *talking* about their bodies, including the materiality of their embodied experiences. Following this, participants were asked how their experiences with cancer had impacted on their sexuality (if at all). 'Sexuality'

was purposively left undefined to allow participants to make sense of what this meant to them in the context of their experiences with cancer and everyday lives. A range of responses were elicited, including talking about the act of sex, feelings in a relationship, sense of self when walking down the street, energy, fatigue and attractiveness. The fourth question asked participants how their experiences that had been discussed in the interview thus far had impacted on the way that they saw themselves (if at all). Participants were then asked how they had managed the changes that had occurred to their bodies, including both emotional and psychological coping strategies, as well as practical measures and care practices that had been taken up to cope with the changes they had experienced as a result of cancer. Participants were asked if there was any other material they would like to add, or anything they felt had not been covered that they would like to talk about. And finally, the participants were asked how they had found the experience of talking about cancer and sexuality. The prompts used throughout the interviews were designed to elicit accounts of how changes had occurred over time, the emotions that were associated with the experiences, and if any positive experiences had occurred.

After the first five interviews were conducted, the audio recordings were professionally transcribed and a preliminary analysis conducted to check that the interview schedule and interviewing approach was gathering information that would enable the research questions to be answered. This was found to be the case. However, more prompts where added to elicit responses with more context and in-depth descriptions of experience occurring over a

period of time. Prompts for positive changes or experiences around sexuality post cancer were also added to see if these were occurring and that the interview was not purely focussing on negative experiences of sexual embodiment following cancer.

The interview schedule was also reordered slightly following the pilot interviews. The original schedule had asked questions about changes to perceptions of self before discussing sexuality; this was reversed to reflect the flow in the types of responses that were already occurring in the first half of the interview. The reordering of the schedule allowed for greater flow throughout the interviews and more specific prompting for experiences of both sexuality and perceptions of self to be discussed.

# Constructing the interview: Co-constructed, intersubjective.

The interviews and the analysis that form this study draw on the conception of the interview as co-constructed and intersubjective. In the co-constructed interview, both the participant and interviewer position themselves and the 'Other' through language (Davies & Harre, 1990). The constructions drawn on by both participants in the interview are embedded within the wider social context, and existing cultural and institutional structures that shape the context of interview. As such, participants often draw on wider cultural markers to make sense of the other person in the interview and the interviewing process, including cultural constructions of the female body, as well as those meanings that are related to the actual bodies of the interview participants (Rice, 2009).

### Mode of communication: Telephone and face-to-face interviews.

While I had initially hoped to do more face-to-face interviews as part of this study, I soon realised due to geographical restrictions many of the interviews would need to be conducted over the phone. There is some discussion in the literature as to whether telephone or face-to-face produce different interactional effects, potentially shaping the type and quality of responses elicited from participants in qualitative interviews (Irvine, Drew, & Sainsbury, 2013; Sturges & Hanrahan, 2004). The importance placed on modality and the consideration of contextual factors in part depends on the aims of the particular study (Sturges & Hanrahan, 2004). In this case, interviews were designed to elicit descriptions, stories, and accounts of women's experiences of sexualities and bodily experiences in the context of cancer for the purposes of conducting qualitative analyses.

Interviewing face-to-face inevitably raises the possibility of embodied communication that is not conducted through the discursive presence or absence of spoken words. As such, there were interactional differences in the discursive recourses that the participants (both interviewer and interviewee) in the interview drew on depending on the mode of communication. Face-to-face communication allowed eye contact, and the reading of facial expressions and body language that contributed to the production of the interview interaction. In face-to-face interviews, the women indicated changes, scars and sites of loss on their bodies as embodied gestures within the interview. For example, Philippa showed me her hysterectomy scar and a photo to allow a comparison of her hair pre and post-cancer. While this was possible for the four interviews

that were conducted in person, the use of the phone to conduct interviews removes the visual aspects of embodied communication. During telephone interviews, I was aware that I was constructing the women through their voices, manner of speech, negotiation of rapport, descriptions of bodily change, and verbal indications of emotion and distress, including periods of silence when I was not able to see them. However, the non-visual aspect of telephone interviewing may have encouraged a tendency to give richer descriptions when referring to aspects of the body that could not be seen. In a couple of interviews I was aware of the embodied actions of participants by the lowering of their tone of voice which indicated that they were looking down at their bodies at that moment in time, giving descriptions of scarring, radiation and cosmetic tattoos, and surgical locations on the body.

Experiences of cancer, sexuality and body changes raise particular issues that are important to a discussion of the mode of communication used in this study. It has been suggested that telephone interviews can be more suitable for interviews regarding topics which are sensitive, and potentially embarrassing, and less suitable for interviews which are more highly emotional (Sturges & Hanrahan, 2004). The interviews in this study covered topics that were both sensitive and emotional. These include the highly sensitive nature of talk about personal experiences of sexuality and bodily change, and the strong potential for anxiety, given the often private and socially taboo associations with these topics (Little et al., 1998; Manderson, 2005; Meerabeau, 1999). Furthermore, there is also a strong level of emotion often linked to these issues, given significant degree of change, grief and loss

often experienced by women with cancer (Thomas-MacLean, 2004a). Overall, I found that there were advantages to interviewing over the phone. During the interviews, I felt that some participants found the convenience and level of anonymity helpful given the sensitive and personal nature of the topic.

However, there were other times when I felt that had I been able to conduct a face-to-face interview I may have been able to engage with non-verbal communication cues that supported the women further at times during the interviews, particularly when verbal communication became challenging due to emotional distress. Conversely, in a face-to-face interview with Laura, I felt that it may have been more advantageous to conduct the interview over the phone, as it may have lowered the level of emotional confrontation for her and distress.

## **Analysis of Interviews**

The analysis of interviews took the form of transcription and an initial thematic analysis that allowed me to describe, organise and become more familiar with the content of the interviews. The main analysis that was conducted was a thematic discursive analysis from a feminist poststructuralist perspective (Gavey, 1989). There is no 'one' approach to conducting such an analysis and a multiple interpretations are possible through a process of reading and re-reading and engaging in reflexive theoretically informed questioning of the data (Gavey, 2011). The underlying assumptions adopted and process of analysis conducted is discussed below.

### Transcription.

In this study, transcripts were not regarded as objective pieces of evidence, but rather subjective representations of the interview (Kvale & Brinkmann, 2009). The transcription for this study was conducted by myself as part of the process of analysis (Parker, 2005b). A significant level of detail was initially incorporated into the transcripts, including indications of pauses, intonation, disrupted words, corrections, interruptions, laughter, fillers such as "um", and other verbal cues used by the interview participants. The initial interviews that were conducted as part of the pilot were originally professionally transcribed, then quality-checked and re-transcribed by myself to include the same level of transcription detail in order to provide consistency and assist the overall analysis. These transcripts, along with the sound recordings and my interviewer field notes, including reflections on embodied communication, were included in the analysis. Interview transcription extracts were simplified in the presentation of extracts in the analysis, as the symbolic and material aspects of embodied sexual subjectivity were drawn on increasingly as the analysis was worked through, and in order to strengthen readability. However, the following transcription conventions were retained in the final presentation of data to retain meaning within the participants talk: Three periods, "...", indicate where text, which was not pertinent to the extract in the context of analysis, was removed either at the beginning or end of longer quotations, or in the middle of a quotation; round brackets, "( )", were used within quotes to indicate the sounds, pauses and changes in intonation that were used to produce meaning within the talk; commas, ",", were used to

indicate slight pauses in the talk; dashes "-" accompanying a word, or part of a word, indicate a word that was cut off during talk; italicised words were used in participant talk to indicate a word that was particularly emphasised by the participant to influence the meaning; square brackets, "[ ]", were used to insert words that were missing from the participants' talk to retain the extract's meaning when presented in the analysis away from their original context; finally, the inclusion of my talk as the interviewer is included in italics, including within round brackets when this was included as part of shorter quotations reported within the discussion.

### Thematic discursive analysis.

A thematic discursive analysis was conducted, employing a poststructuralist approach to discourse (Gavey, 1989), and drawing on thematic decomposition to inform the organisation of themes according to the subject positions adopted by the women in their accounts (Stenner, 1993). In order to account for the 'personal' and social contexts of which these interviews were a part, I decided to use a methodology that collapsed the distinction between self and society, allowing cultural and socio-political contexts to be positioned as integrative to subjectivity. From a poststructuralist perspective (Gavey, 1989), this would allow the full extent of experience accounted for by the women to be captured. By taking up a poststructuralist approach to discourse analysis, I was able to analyse the women's accounts of embodied subjectivity in a way that addressed the fluidity of 'the body' across social contexts and the significance of dominant social discourses relating to gender and heterosexuality. Further, women's agency in constructing their

sexual subjectivity could be examined, as well as the manner in which social contexts impede and facilitate the intrapsychic experiences of the women. In other words, this approach to analysis would allow the extent to which gendered discourses pervade everyday 'personal' lived experiences to be addressed, while highlighting areas for social change (Gavey, 1989, 2011). Two levels of analysis were conducted. The first involved a preliminary thematic analysis that described the content of the data. The second level involved organising the data into overall coherent themes and examining the patterns of women's constructions of experiences and subjectivities within these themes (Stenner, 1993).

For the purposes of this analysis, 'discourse' was taken to refer to shared social meanings within language that are culturally and historically specific (Foucault, 1984). Not all discourses are equal, but organised by the materiality of social structures and institutions, cultural imperatives, and everyday experiences (Foucault, 1963). Such discourses are taken up as sexual 'norms' and practiced through embodied actions and within intersubjective relational contexts (Butler, 1990). Dominant social discourses are those that appear 'neutral', 'natural' or 'common sense' and tend to be taken for granted as legitimate constructions of experience (Foucault, 1963). From a feminist perspective, the pervasiveness of such discourses is particularly important, as they tend present a bias towards masculine constructions of 'reality', which decentre women's subjective experiences (Brooks, 2007). Such dynamics of discourse produce particular possibilities and constraints for women's subjectivity (Gavey, 1989), and function to facilitate or impede particular

intrapsychic experiences (Jack & Ali, 2010), including psychological distress and emotional regulation (Lafrance, 2009; Ussher & Perz, 2010).

The interview texts formed the focus of analysis for the study (Potter & Wetherell, 1987). The assumption was made that the texts were constructed of language that was not neutral or transparent, but shaped by the possibilities and constraints of discourse and the materiality of the body with cancer, as well as the women's intrapsychic negotiation of their embodied experiences of cancer. As part of the theoretical perspective adopted, the 'subjectivity' of the women was assumed to be produced within language and according to the discursive practices actively employed by the women as subjects. In other words, the discursive resources adopted by the women constructed their meanings and positioning of their 'selves' in relation to discourse (Burman & Parker, 1993), including experiences of embodiment. Rather than locating subjectivity within the private individual, subjectivity was assumed to be produced through socio-cultural context, on a continuing basis through the discursive constructions of language. Therefore, in conducting the analysis I was interested in the women's talk, both as active agents in negotiating particular discursive positions in the interviews, and also as subjects who are constructed by discursive resources they employed (Davies & Harre, 1990). When conducting the analysis, I focused attention on the forms of discourse and the discursive resources that the women used to account for their embodied experiences with cancer and sexuality.

At the first level of analysis, an initial thematic analysis was conducted to organise, describe and familiarise myself with the patterns and content of

the interview accounts. In conducting the thematic analysis, I first thoroughly familiarised myself with the interview material (Braun & Clarke, 2006). This included the transcription of the interviews, conducting quality checks of transcriptions, further reading and re-reading of the interviews, and returning to the sound recordings to clarify meaning and expressions of speech throughout the process. Familiarisation, reading and re-reading were conducted with the aim of getting a 'sense', or ideas for potential themes (Boyatzis, 1998), which would be used to meaningfully organise and describe the data as a whole. As potential themes were identified they were checked back, both across, and within transcripts for their ability to capture patterns while retaining meaning that was distinct from other themes within the analysis. An initial coding framework was created in this process, which was then used within a line-by-line reading of the data to systematically collate instances of each theme. The coding of the data included the example of the instance of the theme as well as context that was relevant to the production of that material. In acknowledgement of the co-constructed, intersubjective production of these accounts, my own actions as the researcher were included in the coding and analysis as they contributed to the particular instances of each theme. However, these were most often removed in the final analysis, except where explicitly relevant, to improve readability and as the extracts were selected to illustrate particular phenomena relevant to the analysis.

After familiarising myself with the interview texts by conducting the interviews, transcription, quality-checks, and the completion of a thematic analysis, a second level of analysis was conducted to organise the data

according to three overall 'higher order' themes had been identified through the first level of analysis (Stenner, 1993). The three overall 'themes' were chosen as representing the main aspects of the collective 'story' of women's sexuality after cancer as it was contained within the accounts and reflected the subject positions that the women adopted in their accounts, including, 'The Medical Body', 'The Abject Body' and 'Positioning Embodied Sexual Subjectivity Inside and Outside 'Sex''. Informed by a feminist poststructuralist perspective, each of these themes was tied to particular symbolic and material experiences, and had particular implications for the women's intrapsychic experiences that are discussed in the analysis.

The second level of analysis focused on the content of discourses within the themes, including how discourses functioned within the women's accounts (Potter & Wetherell, 1987). On a more detailed level, more specific theoretically informed questions were reflexively asked of the interview accounts (Gavey, 1989). Examples of these questions included the following: What is 'the body' and 'embodiment' according to the constructions being used by the women in different parts of their accounts? What is 'sex' and how is it being constructed and experienced by the women throughout their accounts? What is 'sexuality' and how is it being constructed and experienced by the women throughout their accounts? Where, in relation to the women's sexual subjectivity, is 'the body' being positioned by the women throughout their accounts? How do different social and relational contexts inform how 'the body' and 'sexuality' are constructed and experienced by the women?

'femininity' for the women in different parts of their accounts? How does intersubjectivity (or imagined intersubjectivity), particularly in the form of heterosexual couple relationships, inform how 'embodiment', 'sexuality' and 'femininity' is experienced and constructed by the women? What prevailing discourses do the women adopt, and how are these negotiated across the women's accounts? Where are 'silences' and 'norms' being taken up in the women's accounts and what implications does this have for the women's subjectivity? And finally, what are the implications of the women's constructions of sexual subjectivity on their experiences of 'sexuality', 'femininity' and body changes following cancer, including intrapsychic experiences?

Through the process of reflexive questioning of the interview texts, meaningful patterns of subjectivity were identified across and within the accounts. The accounts were then checked back, to follow up on all instances of such patterns with commonalities and variability within the women's accounts noted. This process also involved taking into account the way that subjectivity was orientated in the women's talk through content about subjective experiences, including intrapsychic experience and social context. In presenting the final analysis, each section of analysis contains a 'story' that reflects the particular patterns of subjectivity that were identified.

When analysing the women's accounts, I was careful to avoid conducting a discursive analysis that would result in positioning the women in a way reduced their subjectivity purely to discourse positions, an action some researchers have referred to as discourse reductionism (Parker, 1997). For

example, I was wary of producing an analysis where the women were positioned purely according to particular dominant discourses, without attending to the subtleties of how embodied sexual subjectivity was both accounted for, and negotiated, in the interviews. Such subtleties included the tensions, nuances and fragmentation of subjectivity, how the women negotiated their own agency, and the importance of the emotional content and context of the interviews. The women's embodied subjectivity was not conceptualised as 'fixed', rational or unitary, but non-linear and fragmented over the course of cancer treatments and social context.

### **Analysis Outline**

The following chapters will demonstrate the analysis that was conducted. Firstly, 'The Medical Body', which will examine the women's constructions of embodied sexual subjectivity across the cancer chronic illness trajectory, including interactions that the women had with the medical system. Secondly, 'The Abject Body', will be discussed, including the ways that women constructed their bodies as 'abject' with implications for their sexual subjectivities. And finally, the subject positions that women adopted in relation to the social construction of 'sex' will be examined, including the discursive and bodily practice undertaken to take up a subject position within 'sex', as well as the experiences that led the women to position their bodies outside 'sex'. The implications for the women's sexual, feminine and relational subjectivities will be discussed.

### **Chapter Five: The Medical Body**

The analysis of 'The Medical Body' both describes the women's experiences of their bodies and sexualities across the cancer illness trajectory, as well as informing the context of the women's experiences of embodied sexuality that are discussed in the following analysis chapters, 'The Abject Body', and 'Positioning the Body Inside and Outside 'Sex''. The women in this study constructed an illness trajectory with cancer, in which they transitioned from positioning their bodies as 'subject', to 'object' and 'ill' under the medical gaze during cancer diagnosis and acute medical treatment (Foucault, 1963). At the conclusion of acute treatment, the women reported a return to positioning their bodies as 'subject', and often had to live with significantly different bodies compared to prior to cancer. Many of the embodied changes from cancer treatments had an impact on the way the women experienced and made meaning of their bodies, 'selves' and social contexts (Williams, 1996). Subsequently, the women managed their embodied sexual subjectivity in the context of continued uncertainty that was associated with the risk of cancer recurrence, and the discursive, physical, and emotional effects of cancer and cancer treatments.

Cancer can be positioned as a chronic illness, due to the ongoing risk of recurrence, as well as the corporeal and biographical challenges experienced by people who survive cancer treatment (Little, 2004). The women's constructions of embodiment and sexuality in the context of illness and the medical system can be interpreted through the use of Williams' (1996) theory of embodiment across the chronic illness trajectory. Williams describes

the changing experience of embodiment across the trajectory of chronic illness suggesting that the experience of 'normal' embodiment can become disrupted by the presence of illness, causing the body to become the "thematic object of attention" (1996, p. 24). Physical sensations and symptoms become more physically present in everyday life, causing the body to appear, or dysappear (Leder, 1990, p. 69), as 'dysfunctional', bringing about a state of dualistic embodiment referred to as 'dysembodiment' whereby a separation of experiences of the body as subject and object is emphasised (Williams, 1996). Further, dualistic experiences of embodiment are reinforced through interactions within the medical system, including the technical use of medical language that constructs experiences of embodiment. According to Williams, individuals make attempts at 're-embodiment' when they engage in biographical meaning making of the changes in the relationships between "body, self and society" (Williams, 1996, p. 32), and manage new bodily states that are brought on by discursive, intrapsychic and material complexities of chronic conditions. States of 're-embodiment' remain fragile due to the complexities of discursively and materially managing the body, leading to a tendency for people to continually move between states of 'dysembodiment' and 're-embodiment' (Williams, 1996).

This chapter will firstly focus on the women's experiences of the 'body-as-object', including the transition into the medical system through cancer diagnosis and treatment of the 'body-as-object' within the medical system. Experiences of the 'body-as-object' will be examined, including instances in the women's accounts where they contested official medical

narratives through their subjective experiences of illness and the uncertainty of the cancer journey (Purkis & van Mossel, 2008). Further, many of the women continued to experience their bodies as dysfunctional and 'object' into recovery, with consequences for 'sex' and sexual subjectivities for some of the women. The women's experiences of the 'body-as-subject' will then be discussed, including positive experiences within the medical system, and constructions of biographical meaning making around cancer experiences, and experiences of 're-embodiment' in relation to 'sex' and sexual subjectivities (Williams, 1996). While the chapter is divided into two overall sections for the purposes of describing the findings of the analysis, there was movement between 'body-as-object' and 'body-as-subject' subject positions by the women in their accounts. For example, as discussed in the analysis below, some of the women resisted medical discourses and also took up 'body-assubject' positions during treatment. Movement between states of 'dysembodiment' and 're-embodiment' during recovery further demonstrated fluidity between 'body-as-object' and 'body-as-subject' subject positions within the women's accounts.

It will be argued that the process of cancer treatment produces instances in which embodied sexual subjectivity is often negotiated and renegotiated around institutional constructions and the lived constraints of women's bodies with cancer, across the illness trajectory.

## The 'Body-as-Object'

As outlined in this section, the women in this study adopted biomedical discourses to construct their bodies and experiences with cancer. In addition, the women were also positioned by the medical system according to biomedical constructions of embodiment, illness, femininity and heterosexuality. Within biomedical discourse, the body is positioned as a natural object that is separate from socio-cultural context (Gordon, 1988). The positioning of the body in this way allows the body to be read in terms of biological knowledge of it's functioning, assessed according to risk, and treated to preserve life and minimise the destruction of cancer on the body. By taking up biomedical discourses of the body and positioning the 'body-asobject', the women constructed a changed relationship with their cancerous bodies in which they split subjective notions of their embodied subjectivity from the 'body-as-object'. Further, by positioning the 'body-as-object' through biomedical discourses, the women's bodies were removed from discourses of sexuality and femininity. The positioning of the 'body-as-object' continued into 'recovery' for many of the women, with implications for the women's sexual subjectivity.

Diagnosis: Transition from the 'body-as-subject' to the 'body-asobject'.

A diagnosis of cancer marked the transition from constructing the 'body-as-subject' to 'object'. Cancer diagnoses functioned to mark the women's bodies as cancerous and position them within the medical system for the duration of cancer treatment, as well as being at increased risk of cancer recurrence in the future (Sulik, 2009). Through medical diagnosis, the women's bodies were brought under the medical gaze, transitioning the body from subjectively belonging to the women, to an object that is able to be identified through technical medical language, compartmentalising cancer within the body and positioning the women's bodies within biomedical discourse (Foucault, 1963). Examples of the women positioning the transition of their subjectivity between the 'body-as-subject' and 'body-as-object' was evident in the language that was used to refer to diagnosis and the existence of cancer within the body. For example, the women most commonly positioned their diagnosis as a 'body-as-subject' experience, saying, "I was diagnosed", "I got diagnosed" (Holly), or "I found out that I had" (Ellen). These accounts of diagnosis positioned cancer as both a material biological entity and as part of the body belonging to that person, which explains the use of the terms "I was", "I got", and "I had". Other constructions of cancer in the women's accounts were exclusively 'object', in which cancer was positioned as a foreign and destructive object within the body that was separated and compartmentalised from the subjective body. For example, the women referred to cancer in their accounts as "it", "the cancer", "the cancer cells", or "the tumour". The diagnosis of cancer marked an event in the women's accounts in which a state of dysembodiment arose (Williams, 1996), and the 'body-as-object' became more visible due to the materiality of the body as ill, at risk, and requiring medical treatment. The diagnosis of cancer subsequently served to legitimate medical interventions and positioned doctors as experts over the naming and functioning of the 'body-as-object' with cancer,

regulating practices that are conducted to the body through the construct of a 'neutral' and 'objectifying' gaze (Foucault, 1963).

In addition to recognising the materiality of cancer within the body, a cancer diagnosis also signalled biographical disruption (Williams, 1996), and the positioning of the women's subjectivities according to cultural discourses of cancer and illness (Willig, 2011). Cultural constructions of cancer often employ military metaphors to construct the disease as an invasive growth, which occupies the body through a destructive bodily force that attacks from within (Sontag, 1978). The confirmation of the presence of cancer signals the possibility of death and the need for counter-attack in the form of medical treatments, in order to overcome the invasion of the body. In managing discourses of cancer as a destructive threat within the body, the women moved between positioning their bodies as subjectively their own, to biological objects that were given over to the medical system to be assessed and treated. For example, Jackie described the steps involved in her treatment of skin cancer, saying,

I got a um squamous cell on my face and um had that removed but they didn't get it, so then I had to have radiation and then about twelve months ago I got the all clear on that because it had actually gone in to my nervous system.

At other points in their accounts, the women managed their subjectivity by adopting biomedical discourses that compartmentalised cancer within their bodies, or materially identified the eradication, or separation of cancer tissue

from healthy body tissue, through the effects of medical treatments on the body. For example, Sonia adopted biomedical terminology of her surgery to describe her decision to have her breasts removed, saying,

So I elected to have um, what they call a prophylactic, what doublewas it? A prophylactic bilateral mastectomy to have them removed.

By positioning the body with cancer in this way, the women adopted a dualistic construction of embodiment in which the 'body-as-subject' and the 'body-as-object', like the mind and body, are able to be distinguished and managed separately. Subsequently, biomedical discourses were adopted, which functioned to discursively contain cancer within the body, splitting the body-as-object from the body-as-subject and distancing the women's subjectivity from existential threat.

Biomedical discourses of risk were taken up by the women in their accounts, which functioned to further reinforce the legitimisation of the medical gaze of the 'body-as-object' and the importance of materially and discursively taking up the 'fight' against cancer. The women often rated cancer diagnoses for their risk level or treatability by referring to the stage at which the cancer was diagnosed and the medical prognosis, with some cancers labelled a "better cancer to have" (Joanna) due to an increased likelihood of survival and the need for less invasive treatments. For example, in Joanna's case, her primary diagnosis was changed from colorectal cancer to anal cancer. Colorectal cancer presented a greater life threat for Joanna and would have required surgery, the possibility of a stoma bag, chemotherapy and

radiation, while anal cancer was treated with radiation and chemotherapy and given a higher chance of survival by doctors. She referred to the different diagnoses and related treatments, saying, "I know cancer's cancer, but it was a better cancer to have". In accordance with biological understandings and discursive constructions of the disease, cancers were attributed agency by the women, most often described as "aggressive", "invasive", or by Jackie as, "a bit of a slow grower". All of the women positioned their cancer diagnoses as a serious risk, with the exception of Joanna, who had a secondary diagnosis of thyroid cancer and said,

I know it sounds horrible, but after you've dealt with anal cancer, thyroid cancer's such a walk in the park.

Biomedical discourses of risk subsequently reinforced the emphasis on survival within interactions with the medical system. Some of the women also spoke of their willingness to enter into medical treatment and give their bodies over to medical professionals in order to ensure survival, as Sonia said, "first thing was just cut it out and get rid of it (*Mm*) there was no hesitation". Entry into medical treatment was constructed as a dichotomous choice; treatment would support the possibility of survival and life, and abstaining from treatment would result in death. For example, Eva said,

I was, in terms of the um the surgery and stuff, it was like, have the surgery or die basically so I was quite happy, to have it.

The possibility of death often remained with the women throughout treatment, as demonstrated by Gwyn when she said:

I think the my reaction to the menopause was sort of subsumed by the whole you know worrying about whether the cancer was um, you know responding to the treatment and whether I'd be alive in a year's time.

Biomedical discourses positioned the body-as-object as 'risky' and as containing a disease with it's own form of agency, signalling a loss of control over the body of the women. By adopting biomedical discourses of risk, the women positioned their 'object-bodies' as being in need of medical containment, reinforcing the need for further medical knowledge and treatments. Positioning the body in this way reinforces the split between the 'body-as-subject' and 'body-as-object', privileging discourses of biomedicine and survival over embodied discourses relating to the women's sexual subjectivity.

### Medical treatment of the 'body-as-object'.

Following diagnosis, systematic treatment within the medical system was begun. Like other studies examining subjectivity in regards to medical treatments (e.g. Manderson & Stirling, 2007; Waskul & van der Riet, 2002), most of the women spoke about their cancer treatment with little to no indication of their own agency. The construction of the 'body-as-object' was also demonstrated in the women's accounts of the different modes of treatment received, despite the effects many of these treatments had on the women's subjective experiences of their bodies and sexualities. Nearly all of the women received surgery for their cancer, adopting a construction of the

'body-as-object' in their accounts of surgery. In this construction, surgery was often spoken about as an assumed and legitimate outcome of a cancer diagnosis. For example, as Ellen said,

I found out that I had endometrial, or you know, uterine cancer. Um (soft laugh) so I had a radical hysterectomy...

And, Eva said,

...it actually turned out that the cancer had stopped responding to the radioactive iodide treatment, um, so at that point ah the only option was to operate.

Similarly to these two examples, many of the women listed their cancer treatments as events within a chronological trajectory, without any reference to their own subjectivity in the process. As such, the women tended to use a "passive construction" to talk about their experiences of surgery (Manderson & Stirling, 2007, p. 83), meaning that the treatment was something that happened *to* them, without a sense of their own agency in the process. For example, June said, "When you sort of, you know, you're told you'll have a mastectomy...", and Marie said, "so now I've been reconstructed...". Surgery was also described in terms of "loosing", "removing" or the "taking" body parts and cancers. A couple of participants referred to "cut out" cancers, or "cut off" parts of the body. For example, Robyn talked about the removal of her reproductive organs, saying,

And had a, a total hysterectomy. Um, which included sort of removal of the ovaries and fallopian tubes (pause) with that and they-they found that was, considered that to be enough.

The construction of the 'body-as-object' in accounts of surgery was further demonstrated through the objective positioning of parts of the body that were affected by cancer surgery, including the distancing of the body from symbolic meanings of femininity and sexuality usually associated with particular parts of the body. Examples of this included, "the ovaries" and "the left breast". Constructing the body in this way separated the diseased parts of the body from the rest of the body. Manderson and Stirling (2007) suggest that the use of objective medicalised language in the context of breast cancer allows women to talk about their surgery in a way that is less "hurtful" than saying, for example, "my breast" (p. 84). It is possible that this function may extend to other parts of the body as well, however, the distancing of the 'self' from the removal of body parts is particularly significant in the context of the social meanings associated with breasts, as visible physical signifiers of femininity and part of sexual activity (Langellier & Sullivan, 1998; Ussher et al., 2012; Young, 2005). Further, women's reproductive organs were referred to as "bits and pieces" (Philippa) and "stuff" (Ellen) during descriptions of surgery for gynaecological cancers. Gwyn and Philippa also spoke about doctors doing "clean up" surgeries to remove their reproductive organs and cancer tissue. This may be due, in part, to the lack of social visibility of reproductive organs as signifiers of femininity and sexuality life, and also that none of these women talked about a loss of fertility disrupting future life plans

for having children (Juraskova et al., 2003). It is also possible that this construction of women's reproductive organs may be a reflection of the tendency to repress the corporeality of women's bodies (Ussher, 2006), particularly when this materiality becomes heightened through the corporeality of cancer as a disease and the effects of cancer treatments, a point that will be discussed further in the following chapter.

Consistent with cultural constructions of cancer treatments (Sontag. 1978), chemotherapy, hormonal treatments and the body's healing function were imbued agency in the women's accounts, as part of the interaction between the 'body-as-object' and cancer treatments. Chemotherapy was constructed as an 'unnatural' onslaught of chemicals to the body which disrupted 'natural' body chemistry, brain signals, and the physiological and energetic 'balance' within the body. The women attributed significant experiences of sickness during treatment to chemotherapy. In addition, experiences of the loss of sexual desire, incontinence, inability to concentrate, short-term memory loss, and depression were also attributed to the effects of chemotherapy treatment in the women's accounts. For example, when talking about the effects of treatment and the possible return of her sexual desire two years after treatment, Jackie said, "it certainly has had a lot of chemicals to deal with", and in regards to experiencing depression, Marie said, "A lot of it is just the chemicals in your brain just get screwed up by the chemo and it can come on". As such, the constructions of chemotherapy functioned in the women's accounts to objectify the body's functioning, as demonstrated in the quote below from Sonia.

...according to the specialists what happens is with this particular type of cancer and the type of intensive treatment is it turns on the thing in the brain that says 'you have to keep eating to feed the body' cause the body's had all these artificial chemicals, all your body cells have been killed off and damaged and the body's drawing energy, drawing energy, drawing energy.

Similarly to chemotherapy, hormonal treatments were also positioned as having active agency against the body's 'normal' functioning. Further, hormonal treatments also often had detrimental effects for the women's sexual functioning in their accounts of hormonal treatments, with the agency of the women tending to be constructed as absent. For example, Christine said, "once I went on to Arimidex it broke down all my sexual activity", and Jackie said that her hormonal treatment functioned to "turn off my ovaries". As such, chemotherapy and hormonal treatments were constructed as occurring outside the agency of the women, enacting processes on the women's bodies that were attributed agency as part of the interaction between the body and medical treatments as 'object'. Biomedical constructions of cancer treatment position the body as a "thing-like" object, (Williams, 1996, p. 27), and construct medical treatments as containing the loss of control of the body signified by the presence of cancer within the body (Sontag, 1978). Similarly, the women in this study positioned the medical system as taking up the 'fight' against cancer, constructing their agency passively in regards to biomedical constructions of medical treatment.

# Experiences of the 'body-as-object' in medical treatment.

While many of the women were given cancer diagnoses that were positioned as treatable by medical professionals, many of the women also reported shock, fear and anxiety at the possibility of death in their accounts. For example, Ellen said, "I mean at the time I just felt so upset and so, scared that I would die and not wanting to die (laughs), stuff like that (laughingly)", and Sonia said, "...for me the early days were shock of 'Shit, I'm going to die'". Further, many of the women reported experiencing uncertainty at the outcomes and consequences of treatment, which were sometimes unknown going into treatment. As Anna said,

They don't really know what effect the treatment has had [on fertility]. Like they just wanted to have conversations pre-chemo, so that we'd have something to go off afterwards.

At other times in the women's accounts, the taking up of cancer treatments produced new experiences of uncertainty. For example, Eva said,

... a couple of- kind of minor things went wrong with the surgery, because the cancer was a lot more um advanced then the scans had really been able to show, um and as a result, half of my vocal cords were paralysed.

Oh wow (softly) yeah

So I had to speak and swallow again.

Accounts of uncertainty, risk and fear of death can be read, in part, as a function of discourses of biomedical risk that, as discussed previously, reinforce the split between the body-as-object and the body-as-subject in taking up medical treatment. However, the uncertainties and risks identified by the women were contrary to the positioning of the diagnosis by doctors, and extended across the illness trajectory. Uncertainty and risk were, therefore, positioned by the women as being uncontained by the uptake and adherence of medical treatments. In other words, medical treatments often did not entirely remove experiences of uncertainty (Purkis & van Mossel, 2008), and often produced new uncertainties through the impact of treatment side effects on the body, including after the conclusion of acute treatment, a point discussed later in the 'The *dys*functional body and recovery' section in this chapter.

The experience of taking up medical treatment was often positioned as something that the women found was difficult to be fully aware of at the time of treatment, including treatments that subsequently affected the women's constructions of embodied sexual subjectivity. Many of the women reported that their interaction with the medical system following diagnosis was "very intense, very rushed, and very full on" (Anna). As Gwyn said, "So um I had all the modalities and in a very short period of time in about ten months. It was [a] pretty, pretty intense treatment schedule", and Lucy said,

So he just w- you know basically said, you need to go to Brisbane now... I ended up having about five operations, the lymph nodes removed, lumpectomy, then a full mastectomy and then my ovaries removed

#### Mm mm

yeah that was all in June.

Many of the women reported seeing a number of medical specialists who dealt with different aspects of the cancer treatment and its effects on particular aspects of body functioning, adding to a sense of initial treatment feeling sudden, rushed, and functioning to objectively compartmentalise the women's bodies under the medical gaze (Foucault, 1963). Subsequently, some of the women also reported experiencing a lack of full awareness of what was happening to them during this time, as demonstrated by Sofia in the following extract.

I think because the initial part of it was such a whirlwind. Um I'd seen seven different specialists in what? I think it was a period of four weeks.

Mm

Um, it was just constant. Didn't really have time to, reflect a lot. Andand time to take in, what was going on.

Some of the women also talked about a loss of awareness during chemotherapy treatment, which was attributed to the effects of chemotherapy on cognitive functioning. Many of the participants reported that they were not able to fully come to terms with their cancer, cancer treatments, and the changes to their bodies at the time of acute treatment due to the experience of "chemo fog" or "haze". For example, Gwyn said,

I had sort of a chemo fog during a lot of the time um, so basically lost about a year and a half where I really don't remember too much of what was happening.

In another example, Laura said,

No, I can't, I can't remember. It just seems so long ago and you know, you're in that chemo haze and I don't remember whole months of my life, so I don't, I find it really hard to go back and remember that.

Changes to the body were often reported as occurring suddenly and were described as being difficult to come to terms with at the time of treatment. Further, many of the women reported not being aware of the extent of body changes, including unexpected changes that affected their sexual subjectivity and experiences of sexual activity. For example, Holly made the following comment when talking about how she lost her "libido" after chemotherapy treatment:

I didn't really get it. I didn't feel that comfortable talking to my doctors about it either, so.

Yeah

I was just like 'Ah, it'll get better'.

In another example, in regards to her experience of vaginal dryness after cancer treatment, June said,

And if somebody had sort of sat down and said, 'Well, look, you might have problems sexually, you can use this sort of thing or that sort of thing', because you really don't know, and you feel like you're going to the supermarket and sort of hunting around like young people looking for condoms and that sort of thing.

Accounts such as these suggest that many of the women were not aware of how their bodies would be affected sexually at the time of medical treatment. These accounts demonstrate that the women's experiences of the 'body-as-object' within the medical system were sometimes problematic due to the difficulty that the women had in being aware of the changes to their bodies, and the implications of these changes for life beyond acute treatment, including the women's ongoing sexual subjectivities.

In addition to uncertainty, risk, and the sexual consequences of treatment, the 'body-as-object' was linked to different experiences of the body within medical interactions compared to prior to cancer. As part of giving the body over to the medical system for treatment, Joanna, Sofia and Marie spoke about the experience of having aspects of their bodies, that were usually positioned as 'private', made public through medical interactions (White et al., 2013). Medical treatment gave rise to interactions which included the removal of clothes, displaying parts of the body usually positioned as 'private' and 'sexual', and having conversations with health professionals while undressed and medical procedures were conducted to the women's bodies. For example, Joanna said,

Nothing really bothers me anymore. I have to laugh when I go to the doctors and they say 'oh give it, get behind the curtain and take your clothes off', and well, I have no dignity left (laughs).

Sofia referred to the changed positioning of her body in medical interactions, as well as the presence of the male gaze when she said,

I had to get used to the idea of 'pants down, lie down', complete strangers in the room, 'take your pants off. Lovely' (short laugh)

Yeah, how did you find that? Cause that's-

Oh, it didn't matter when it was the girls, it was only when it was the boys.

With the exception of Sofia referring to the presence of the male gaze in some of her medical interactions, none of the women who reported these experiences described them as negative; however, they did note the exposure of usually 'private' aspects of their bodies as different to 'normal'. For example, all of these women noted a lack of feeling embarrassed at the exposure of their private bodies to medical professionals and discussed these instances with humour, distancing themselves from the implications of transgressing boundaries that function to contain the sexual body (Waskul & van der Riet, 2002). Prior to giving the body over for medical treatment, embarrassment would have usually taken place when private and sexual parts of the body were exposed to non-intimate others. As such, there was a distancing from subjective sexual meanings usually attached to the private

body as the body took on 'asexual' positioning within a systematic public space and was produced as an object of medical treatment.

Finally, a few women contested the positioning of their subjectivity within the medical system, speaking about losing their individuality due to the objective focus of medical practice and knowledge on their bodies. For example, Sonia said, "I find ah, um yeah that their tick and flick really woworks okay if you're in partic- it's very generic and it's overly generic" and Joanna said, "Um because the oncologists are so, keen on curing you, they really don't want to deal with anything else". June said the following when talking about the lack of information and support she experienced around sexual changes following her cancer treatment. She also positioned me as the interviewer and someone working within 'psychology', saying,

I know, look, all health professionals, and you'll find this, you're all extremely busy, and you're looking at it from a clinical point of view, and the patient's looking at it from a personal sort of view.

June's comment demonstrates a construction of the split taken up within the medical system between the body-as-object ("clinical") and the body-as-subject ("personal"), in which she positions patients as being concerned for their own personal wellbeing in a way that is not accounted for within an objective medical construction of survival. In addition, the absence of personal agency under the medical gaze was also part of an experience of being an individual "subsumed" within the medical system. In another example, Sonia

spoke about a loss of individuality within the medical system through physical dependence on health professionals while ill with cancer, saying,

I mean you are really subsumed. You can- especially when you're so weak and you have, um it's- it's similar to a prisoner of war syndrome believe it or not, (inhale) when your entire fate is in someone else's hands. Everything you do whether that might be going to the toilet, or brushing your hair, you can't brush your hair, um doing your teeth you can't do your teeth y- y- just basic things where your entire life is cocooned in such a way, that you don't have control over any of your functions, and that is quite frustrating when you're being told you should have this and you should have that and this is how this is done and this is how this is done. And then you have somebody you have someone like me who comes along and says 'No, well I don't think so' and they didn't know what to do with me.

In this extract, Sonia takes up a metaphor of war (Sontag, 1978) to describe the psychological state of giving one's body over to the medical system for treatment and the associated loss of agency. She positions herself as both dependent on the system due to the state of her body as 'ill', and still actively resisting and disrupting processes within the medical system through her interactions with medical professionals, retaining her agency in making decisions about her treatment. Such accounts can be seen as these women resisting a biomedical discourse focus on the 'body-as-object', and emphasises the subjective experiences of the women within the medical system.

## The dysfunctional body in 'recovery'.

In the women's accounts of experience following the conclusion of acute treatment, many of the women spoke about the number and range of physical changes and difficulties that they were experiencing, including the ongoing effects of longer-term hormonal treatments. Most physical changes were the result of cancer treatments, some of which resulted in new diagnosable medical conditions that needed to be treated or managed. Physical problems reported by the women included osteoarthritis, peripheral neuropathy, lymphedema, fatigue, exhaustion and tiredness, weight loss and gain, speech difficulties, bladder and bowel dysfunction, swelling due to fluid retention at surgery sites, chronic pain, stiffness, soreness, aching, nausea, restricted movement, and areas of numbness due to scarring and tissue damage, and menopausal symptoms, including vaginal dryness. The women often reported experiences of very different bodies than prior to cancer. For example, Christine said, "Because of the excessive tiredness I have been going through and everything I have stopped a lot of things", Philippa said, "[I have] a lot of aches, pains, very stiff and sore type thing", and June said, "And yes, the disks are bulging in my back, in my spine, which is causing more and more pain". The number of issues experienced concurrently and the time they took to resolve, in cases where resolution was possible, compounded the difficulties with physical changes experienced by the women. For example, Joanna reported the changes from her pelvic radiation treatment, saying,

Um, (pause) well, the ah, well the radiation for the anal cancer is pretty brutal. There's no skin left down there anywhere. Umm, so that's sort of, that time was pretty, rough, and the radiation as you probably know, it (pause) it (pause) it- it kills all the stuff down there. So I went into menopause, umm my vaginas, pretty well non-existent anymore, because all the muscles shrink. Umm, my hips are so sore I can- I can-I have trouble walking... Yeah, umm (pause) I'm just always tired (pause) always stiff and sore.

These accounts demonstrate the continuing existence of the 'body-as-object' after the conclusion of acute treatment. Many of the women subsequently continued to experience their bodies as *dysfunctional*, with consequences for biographical meanings of 'self' (Williams, 1996), including sexual subjectivity.

The women often reported experiencing psychological distress after the conclusion of acute cancer treatment, as has been reported in previous research (Thomas-MacLean, 2004a). A number of the women reported experiencing anxiety, and some women reported experiencing depression at the conclusion of initial cancer treatment. For example, Marie said, "...by about June or July I started getting depression and that was diagnosed as quite severe depression and anxiety", and Eva said, "So I've had- I've had trouble um even, even like in the last two years, um with- with anxiety as well". In particular, many of the women reported experiencing anxiety and fear about the risk of cancer recurrence after leaving acute treatment (Thomas-MacLean, 2004a). For example, Joanna said, "it's just that constant thought of what if, what if', and Anna said,

Maybe it will never be over because there's sort of that black cloud that's always in the back of your mind going, 'Just wait. Just wait, I'll be back'.

In addition, Marie said,

...you're sort of pushed through this funnel of treatment and then you're sort of popped out the other side and it's sort of 'we've done our best good luck'... so, you know, you've got that residual anxiety on, what's going to happen, to happen next.

As demonstrated in these accounts, the uncertainty and risk of cancer continued for many of the women past the conclusion of acute treatment (Hubbard & Forbat, 2012; Kaiser, 2008; Thomas-MacLean, 2004a). As such, the positioning of the body as 'object' and unable to be controlled, as signified by a cancer diagnosis (Waskul & van der Riet, 2002), continued for many of the women.

Further to experiences of psychological distress, many of the women also positioned their physical difficulties as acting as a biographical reminder of the presence of cancer in their lives, past the conclusion of acute treatment. The experience of living with ongoing physical and biographical challenges, including changes to sexuality, highlighted the length of time it took the women to 'recover' from cancer, as well as challenging discourses of 'recovery' due to the level of change that had been experienced (Kaiser, 2008). For example, Lucy said,

At the moment I don't even feel like I've got the energy to go out. My day ends, at about, after dinner. Which is really different to my previous life.

Lucy's comment demonstrates a discrepancy between her construction of subjectivities pre and post cancer, based on the extent of bodily change. In another example, Anna directly challenged the notion of recovery when she talked about her discomfort with the term 'survivor' saying, "I feel like I'm on the island. I haven't survived yet." Anna's comment constructs a process towards re-embodiment, which has not yet been resolved. She is transitioning towards a state of embodiment from dysappearing to appearing, although this process has not been completed (Leder, 1990; Williams, 1998). Many of the women reported frustration and disappointment at the level of change, the time it was taking for the issues to resolve, as well as the unknown nature of when, or whether, their bodies would heal. As Lucy said, "I feel debilitated in terms of how my body's turned out", and "in terms of cancer 'Oh it's a big battle', but it's actually all these little battles". These accounts demonstrate instances where the women return to positioning the 'body-as-object', their bodies continually dysappearing as they negotiate 'recovery' (Williams, 1996). Such accounts are contrasted with culturally desirable discourses of cancer survival in which women overcome cancer by returning to their pre-cancer 'selves' (Thomas-MacLean, 2004b). Further, these accounts demonstrate the fragility of 'recovery' and the disruption of continuity in constructions of embodied 'selves' across the cancer trajectory (Mathieson & Stam, 1995; Williams, 1996).

### Sexual subjectivity and the dysfunctional body.

Some of the women reported a significant disruption to their physical ability and willingness to engage in sexual activity following cancer. For these women, constructions of the 'body-as-object' *re*-appeared in their accounts of transitioning outside of the medical system. Vaginal dryness, pain on intercourse, loss of sexual desire, and body changes that contributed to the positioning of the body as less sexually desirable, were all examples of instances where the body could be read as *re*-appearing as 'object' in relation to sex, contributing to a construction of the body appearing and re-appearing as *dys*functional outside of the medical system (Gilbert, Ussher, & Perz, 2013; Williams, 1998). For example, Joanna said,

I don't know physically how much sex I could have because my hips are so sore that there's not a lot of flexibility happening there.

Jackie described an experience of having sex after cancer, saying,

... we had intercourse and it was just horrid um, it burnt the hell out of me, it was so uncomfortable. Um, yeah, it just really wasn't worth it in the end.

Mm

Mm, so. Yeah and to go from I'm talking only a matter of not even twelve months from quite healthy sex life um to abs- you know to not being able to believe that the lymphoma had something to do with that... I think the big thing there was the chemotherapy.

And, finally, Laura described the disruption to sex in her relationship due to her hormonal treatment, saying,

...what I noticed first was that sex became painful.

Yeah

Um, and eventually impossible. Um, I went to see a menopause specialist... and um yeah, he basically said, oh you know, 'Don't use soap in the shower and try these things,' and whatever so, but you know nothing really worked so. That's it (soft laugh).

In each of these examples, the *dys* functional body remains present in the women's lives preventing sex from occurring due to the effects of cancer treatment. Experiences of pain described by Jackie and Laura are also examples in which the body *dys* appears further into view of the women (Leder, 1990), disrupting sexual practices. The significance of pain caused by the *dys* functional body in taking up sexual practices was linked to the disruption of sex for some of the women, signalling a disruption in the women's sexual subjectivities pre and post cancer.

In reflecting on their treatment, some of the women constructed the impact of cancer treatments on their bodies, including changes that had implications for the women's sexual subjectivity, within a 'cost-benefit' framework. Despite ongoing difficulties with a range of side effects, including sexual changes, treatment had ensured the best chances of survival. For example, Eva said,

Um, but, it's, I'm not- in terms of the things that I can't change about my body, I'm happy to have them because it's meant that I'm still here, so the scars and stuff.

And, Marie said,

...at the end of the day as well, one of the things I thought to myself was you know you choose to do it, you choose it for really valid and specific reasons to you know have that- those operations and you knew what the consequences were, there were going to be some ramifications you know around your sexuality and sex...

This was not unproblematic for many of the women, as coming to terms with loss and change due to cancer was difficult. For example, when I prompted Lucy in her interview if she had experienced any positive changes resulting from cancer, she referred to the loss of her job, partner and sexual life, saying, "Um, only being stripped of everything I still exist, so I suppose survival". In the context of discussing a number of ongoing health concerns and concern for her partner due to the absence of sexual activity in their relationship after cancer, Christine reported uncertainty at the cost of her survival when she said, "I suppose in a way, sometimes I feel lucky to be alive and sometimes I feel not". While the survival focus of medical treatment was taken up by the most of the women, making sense of the cancer experience beyond survival was not unproblematic due to significant experiences of loss and the ongoing difficulties experienced in everyday life following the conclusion of acute treatment, including disruptions of sexual practices and subjectivities. Such

accounts suggest that the women were negotiating their embodied subjectivities post-cancer treatments in material and social contexts that indicate the fragility of 'recovery' after cancer (Little et al., 1998), and the range of bodily issues being dealt with while also coming to terms with sexual changes.

### The 'Body-as-Subject'

Some of the women also adopted constructions of their bodies as 'subject' during accounts of positive experiences within the medical system in which they had good relationships with medical professionals, and participated in decision making for treatment and planning for survival. Further, some of the women adopted meanings of their experiences of cancer in which they positioned the 'body-as-subject' as part of making meaning of their experiences of cancer and 'self', transitioning their embodied subjectivity to a state of 're-embodiment' after treatment. Further, a few of the women adopted a subject positioning of the 'body-as-subject' in regards to the re-embodiment of 'sex'.

#### Experiencing the 'body-as-subject' within the medical system.

Having good relationships with medical professionals was reported by some of the women as allowing them to maintain a sense of their individuality throughout the cancer treatment. This was particularly the case for women who felt 'known', or had good working relationships with their doctors. For example, Marie described her interactions with medical professionals, saying,

I've had quite a good relationship with all my doctors, and I think that really helps, you know, where you're not telling the same story to the oncologist as you're telling the surgeon as you're telling the plastic surgeon, they're actually sit down, talk and discuss your case and they're across what the other person's doing and so that's been, really I- I- think having that, comfortable relationship with them has helped a lot. It's given me a lot of confidence that the process is sort of, running, smoothly, yeah.

In this extract, Marie positions herself as feeling confident and comfortable in the process of her medical treatment, due, in part, to the communication between her specialists and the more individualised interactions this subsequently allowed with each doctor. In another example, Christine described feeling valued as an individual by health professionals within the medical system, as the hospital staff afforded her a level of respect and safety that she did not experience from others in her personal life. For Christine, the breast clinic provided a space and form of interaction that allowed her to be more of herself.

Yeah, I, most of the time I sort of, made it as, you know, joking and laughing and everything and I mean, you know, before all of this happened and going through the breast clinic and after the first visit (laughs) everyone knew me, hundreds of people go through, "Oh hi Christine, how are you today?" (laughs)

Yeah, yeah.

You know. While I was there, because no-one, no-one was touching me, no-one was calling me stupid, no-one was demeaning me through it all, so I could be myself there.

For Christine, the experience of being acknowledged and recognised by health professionals contributed to her feeling safe within the medical system. These interactions were positioned positively as they allowed the inclusion of the women's subjectivity in relation to experiences within the medical system and treatment. As such, the positioning of the women's bodies in these accounts is one in which they maintained a sense of their own subjectivity within the medical system.

Some of the women also positioned their experiences within the medical system positively in instances where they were able to retain a sense of agency, control and management over their bodies in medical treatments, including treatments that impacted their bodies and sexual subjectivities post-treatment. Examples of positive experiences included participating in decision-making in regards to treatment and experiencing 'personalised' interactions with medical professionals. Such examples indicate a positioning of the 'body-as-subject' due to the strategies engaged in by the women to actively participate in the management of their cancer in interaction with the medical system, and the biographical meaning making that was associated with these accounts (Williams, 1996). Accounts of decision making in treatment contrasted with the passive constructions of cancer treatment, which were particularly evident in Marie and Sonia's accounts of their decisions to elect to have bilateral mastectomies, and in Marie's case an additional

oophorectomy to prevent ovarian cancer, after a breast cancer diagnosis. For example, Sonia said, "this is my decision and I've thought about this. And so, my specialist had little choice really", and Marie said, "I decided to have my ovaries removed because I'm quite high risk of ovarian cancer so I did that". Both women constructed their decision making about treatment as ensuring their survival past their current treatment by preventing cancer recurrence in the future. In addition, Marie also reported that being a mother also influenced her decision, as she wanted to ensure was able to be around for her children, saying,

... people that I've sort of met along the way have sort of gone 'Oh that's pretty hardcore' the- you know the bilateral mastectomy and stuff and well maybe if I didn't have children or maybe they weren't that age or maybe If I was sixty and not thirty nine or forty I would have made quite different decisions.

For Marie, her treatment decisions were made within the context of other subjectivities that she occupied, biographically making sense of her treatment within the context of her life outside the medical system.

Contributing to experiences of treatment while maintaining subjective agency, both Gwyn and Sonia positioned themselves as able to gather information beyond what was available within the medical system. Gwyn reported that being able to access information on treatment gave her a sense of control over her situation and empowerment within the medical system.

I knew what all the options were, I had the knowledge that I needed to make informed decisions and everything I think that it's not like I was you know on this um, rollercoaster just responding to what the doctors told me. I had opinions and I put in place interventions like the venlafaxine that would've never have been suggested to me I found that on my own.

In another example of seeking information, Sonia spoke about watching a video of a bilateral mastectomy on the Internet to inform her decision to have her breasts removed, saying,

I had researched the operation extensively online

Yeah

And I had watched the operation online so I knew what was coming up.

These accounts contrasted with the passivity, lack of control, and lack of awareness previously discussed in regards to treatment. The women in which accounts position themselves as contributing to their own destiny through cancer treatment, by planning for survival and what life will be like after cancer treatment (Purkis & van Mossel, 2008), including body changes that had implications for the women's sexuality, such as the removal of breasts through surgery. These accounts can be read as instances of the women managing their embodied subjectivity, by taking up strategies to manage the risky cancerous body (Mathieson & Stam, 1995; Williams, 1996), and transitioning towards a state of subjective embodiment by making decisions

within the broader context of their lives beyond cancer and planning for survival.

# 'Object' to 'subject': Re-embodying the dysfunctional body.

William's (1996) describes the process of *re*-embodiment as involving the management of the body and biographical meaning making of illness experiences. There was a point in the cancer journey after the conclusion of acute treatment, which was directly or indirectly described by most of the women, where the physical and emotional elements of their experiences began to be "processed" or "come together". As such, many of the women adopted subject positions in which they demonstrated agency in constructing meaning of the changes to their bodies, sexualities and relationships, as well as the gravity of cancer as a life event.

As part of constructing biographical meanings, nearly all of the women reported experiencing an extensive level of change in their lives following treatment, compared to prior to cancer, with some of the women describing the extent of change as extending to all aspects of their 'being'. For example, Marie, said,

Well I think- like I mean I think when you get the diagnosis it's it- it changes who you are it changes your whole (pause) person. Yo- you know it's like a, you're the same person but it changes your whole, soul your whole spirit. You don't have an experience, like that, and not have it impact you so profoundly to every part of you, every you know, cell of you is impacted and changed by it whether it's your soul or- or

through chemo or through the surgery and all the people that you come in contact with and things you have to do and- all that stuff. It just changes who you are and not in- a sense that you're a- like a personality change but it changes your outlook and your sense of things and stuff like that.

#### And, Anna said,

Like, not one thing, sort of, felt the same as it was or like I could hold on to the whole time. Everything had to at least be shoved to a corner and sorted through to find out whether or not it was going to stay the same or change.

Further to this, some of the women adopted meanings of their experiences with cancer that drew on their increased confidence and awareness of their strength and abilities. For example, Gwyn said she had "...recognition that I have inner strength that I wasn't really aware of", and Joanna said, "I was always a strong person, I'm definitely much stronger". In another example, Jackie said:

I was all of a sudden very very confident in myself. In my looks, in my abilities, um (pause) my (long pause), my temperament, my manner.

A few of the women talked about their resilience and being able to draw strength and understanding from prior life experiences to cope with their cancer experiences. For example, Ellen said Because, I lived in a war zone for a few years, I used to do humanitarian work, and so I think that a lot of the things that people learn through having cancer I sort of learnt through living in war zones.

Further, Sonia positioned her strength in terms of other subjectivities that she occupied in her life, saying:

...if I didn't have a strong marriage and if I didn't have a strong personality individually and I didn't have the support of professionalism behind me, I would have been devastated.

Such accounts demonstrate the agency of the women in making sense of their experiences with cancer, positioning themselves as transforming personally through cancer, and taking up a positioning of the 'body-as-subject'. In contrast to accounts of the lack of control over the body, in these examples, the women make sense of their embodied subjectivity in the context of cancer by constructing connections of continuity between past and present 'selves' (Mathieson & Stam, 1995), creating a continuity of subjectivity across the cancer trajectory that reinforced 're-embodiment' (Williams, 1996), and the positioning of the 'body-as-subject'.

# Sexual subjectivity and re-embodiment.

A couple of the women talked about the importance of time for ongoing healing for the body to physically repair and to be able to become more comfortable in their bodies after being in the medical system. Such experiences contributed to the *re*-embodiment of sex outside of the medical

system. For example, Marie said the following when talking about beginning to become more comfortable with her own body during sex:

I think as the pain recedes and, you see less doctors and you're not just whipping your shirt off, you know whipping your shirt off wheft!

(hand clap)

Yeah

Or you know, not being used as a pincushion, or you know? As you get out of that more and feel like your own person again you get, you know probably the twelve months that will change more again and relax a bit.

Marie talks about lessening pain, positioning her body away from the medical gaze and transitioning towards *re*-embodiment, feeling more like her "own person" over time and thus helping her to "relax" more during sex. In another example, June spoke about her initial self-consciousness about the loss of her breast and mastectomy scar, saying,

Now it doesn't matter, as I said, you learn to live with these things and you just think, you become more comfortable with your own body.

In her account, June positioned sexual changes to her body as something that she learnt to live with, and accept after treatment. In contrast to accounts of *dys* functional bodies and sex, the women take up their bodies as part of their experiences of sex and sexual subjectivities. Both of these accounts can be read in terms of the women transitioning from *dys* appearing to appearing

bodies over time, with the *dys* functional aspects of bodily change receding from view over time (Williams, 1996).

# **Analysis Discussion**

The women's experiences of embodied sexual subjectivity were shaped by the chronic illness trajectory of cancer, structured within the medical system, and constrained by experiences of the lived body with cancer. Many studies have identified a disruption to women's sexual experiences during cancer and cancer treatment (e.g. Andersen, 2009; de Groot et al., 2005; Ganz et al., 1998; Lindau et al., 2011; Meyerowitz et al., 1999). In this study, the disruption to sexuality was identified in the women's accounts as a form of dysembodiment (Williams, 1996), in which the body was positioned as 'object', initiated by the diagnosis of cancer and carried into interactions with the medical system throughout acute cancer treatment. Further to this, the women adopted a construction of their bodies under the medical gaze (Foucault, 1963), and positioned their bodies in terms of biomedical discourses of risk (Sulik, 2009). The women subsequently split their constructions of the 'body-as-object' from the 'body-as-subject', distancing their object-bodies from discourses of feminine sexuality (White et al., 2013), and prioritising survival. From a Kleinian perspective, this splitting could be read as a form of projection of the existential threat posed by the cancerous body, a defence mechanism to rid the psyche of anxiety and fear (Klein, 1946).

The dysfunctional and dysappearing body was characterised in the women's accounts by excess, a lack of containment, the loss of control (Williams, 1998), and uncertainty (Bertero & Wilmoth, 2007; Purkis & van Mossel, 2008; Thomas-MacLean, 2004a). Such accounts included the lack of awareness of the potential impact of treatments on sexual outcomes, as well as continued sexual uncertainty for many of the women due to problematic bodily conditions that had to be negotiated in order to make meaning, and manage embodied changes to sexuality at the conclusion of acute treatment, enabling attempts to transition to states of re-embodiment. Similar to studies documenting positive experiences of cancer (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Lelorain, Tessier, Florin, & Bonnaud-Antignac, 2012), some of the women's accounts of 're-embodiment' were positive and 'transformative' (Laranjeira et al., 2013). However, such accounts of inner strength did not always translate to sexual outcomes and for many of the women experiences of re-embodiment were often problematic, challenging feminine and sexual subjectivities, and resulting in conditions in which the women continually moved between states of dysfunction and re-embodiment (Gilbert, Ussher, & Perz, 2013). As such, the corporeality of the body challenged the adoption and maintenance of feminine and sexual subjectivities. Such accounts highlight the liminality of chronic illness (Little et al., 1998), and the potential for marginalisation of women with experiences of cancer in terms of their sexual subjectivity (Ussher et al., 2012).

The analysis of the medical body in the current chapter can be positioned as part of a larger body of work charting the course of identities

across the trajectory of cancer as a chronic illness, including biographical changes that are informed by bodily events and interactions with the medical system (e.g. Frank, 1995; Mathieson & Stam, 1995; Thomas-MacLean, 2004b; Williams, 1996; Zebrack, 2000). The current analysis extends many of these studies by examining the positioning of women's bodies in relation to sexual subjectivity across the cancer chronic illness trajectory. Similar to the current analysis, uncertainty, risk, and the loss of control, as embodied experiences that are uncontained by the medical system have been identified as significant experiences for people with cancer (Thomas-MacLean, 2004a; Wiener & Dodd, 1993). These issues translate into cultural discourses that structure experiences of the body, including experiences of sexual subjectivity in the women's accounts. Further, the medical system functions to produce subjectivity by constructing patients passively in relation to discourses of cancer within the body, and the structure of cancer treatments (Rose, 2007), reinforcing the women's constructions of the body under treatment as distanced from their sexual subjectivities. Common to these studies is an emphasis on the search for meaning as part of experiences of suffering and the subsequent construction of identities around this process (Little et al., 2002). Accounts from the women in this study demonstrate challenges to making sense of their subjectivities in terms of past and present 'selves', due to the corporeality of cancer challenging discourses of femininity and sexuality.

As noted by Williams (1996, 1998), women experience somewhat different social conditions for embodied subjectivity that extend beyond those articulated in this theory, to include particular gendered experiences of

embodiment. Women tend to be positioned according to the male gaze, with young women positioned as subject to the visibility of that gaze (Calogero, 2004), and older women as invisible to that gaze (Hine, 2011). The subjectification of the male gaze can create the conditions whereby women monitor and regulate their bodies (Bordo, 2003), experiencing their bodies as 'object' as part of the course of everyday life (Fredrickson & Roberts, 1997). Feminine bodies already occupy culturally liminal positions (Ussher, 2006), subject to abject corporeal conditions excessive of bodily boundaries, which tend to be repressed in order to take up more idealised forms of feminine subjectivity within the symbolic order (Kristeva, 1982). In the following chapter, 'The Abject Body', the analysis will examine how discourses of feminine sexual subjectivity are constructed and experienced by women with cancer, drawing on a theorisation of the femininity in the context of abject body changes to examine how women experience marginalisation and stigma in relation to their bodies.

## **Chapter Six: The Abject Body**

The 'abject' body refers to embodied experiences that were positioned outside the 'norms' of bodily functioning, and removed from social constructions of idealised femininity within the women's accounts. The positioning of the body as abject demonstrated a difficulty making meaning, and repulsion towards the body following cancer. Body changes that were positioned as abject were associated with immediate short-term treatment side effects, as well as long-term changes after the conclusion of treatment. Abject body changes included hair loss, scarring, disfigurement, an unhealing mastectomy wound, bowel and urinary dysfunction, an ileostomy, menopause, weight gain, embodied markers of ageing, loss of fertility, sexual problems related to the act of coital sex - such as vaginal dryness and loss of sexual desire - and the presence of cancer, particularly cancers associated with bowel functioning and excretion, such as colorectal and anal cancers. As noted in the previous chapter, some of these body changes were temporary, others permanent, and for others, the outcome was unknown at the time of the interview

Many of the women constructed their bodies as being outside of 'normality' following cancer, and indicated a difficulty making meaning of the body, as well as experiences of horror and repulsion at body changes. Such body experiences challenged hegemonic discourses of feminine embodiment and sexuality, and were positioned by the women as being outside idealised constructions of femininity, and invisible within the male gaze. Many embodied experiences positioned as abject also signified a loss of control of

the body, meaning that the corporeality of the body that is usually repressed and contained through ritual and feminine bodily practices, becomes more visible within the regulatory social gaze. The women's experiences and constructions of the abject body are examined below, within the three themes 'Beyond 'abnormality'', 'Outside the feminine body', and 'The out of control body'. Further, the women's accounts demonstrated subject positions in which the women took up the abject body, and also distanced their subjectivity from the abject body, through practices of management and resistance. Examples of the women taking up the abject body will be examined in the theme 'failure and self-blame', and the subtheme, 'shame'. Managing and resisting the abject body will be examined through the three themes 'concealment', 'resisting discourses of feminine beauty', and 're-positioning the body through personal transformation'.

# **Experiences and Constructions of the Abject Body**

### Beyond 'abnormality'.

Bodily experiences that signified a lack of 'normality' to the women included, disrupted body functions and appearances, as well as the presence of illness. Bodies positioned outside 'normality' were difficult for the women to situate within discourse, meaning that discursive resources were limited for capturing embodied experiences, and that the women's subject positioning subsequently became unsettled and fragile. A few women managed this difficulty by making meaning of the changes to their bodies by constructing

them by what they were not: Not normal. For example, Christine responded to my prompt to describe what her reconstructed breast looked like, saying:

Odd. Not the same as normal, even though I have been operated on this one, it still looks normal. I try to think, you know, it's okay, but I don't see it.

In another example, Lucy differentiated her mastectomy and oophorectomy from prior surgeries, saying:

Um, I see myself, as incomplete

Yeah

Yeah, so missing bits.

Yeah

Yeah? And the missing bits, um, I suppose I've had extra bones before so I've had those cut out and that was sort of to normalise me. This is the first surgery I've had that's definitely not normalised me.

Both Christine and Lucy signal in their accounts that their subjectivity has become 'unsettled' as an implication of positioning their bodies outside 'normality'. For example, Christine refers to unsuccessful attempts to position her reconstruction as "okay", while Lucy indicates that as her body is no longer 'whole', subsequently positioning her embodied subjectivity as being "incomplete". By positioning the body outside 'normality', the women's accounts appear to expose the fantasy and fiction of a unified body (Grace,

2010). In other words, cancer disrupted notions of bodily 'normality' by drawing attention to the corporeality of the ill body (Williams, 1996).

The women's difficulty in making meaning of the body when positioned outside of 'normality' was further evidenced in the accounts of body experiences as "strange", "weird", "bizarre", "freak", "kooky" and "perturbing". The use of such language suggests that the body is positioned not only outside discourses of 'normality', but that these body experiences are unfamiliar. A level of fear and anxiety was also possibly present for some participants, due to the lack of a 'secure' and recognisable location for the body within the symbolic order of meaning (Kristeva, 1982). For example, Anna described her experiences of hair loss during her cancer treatment, saying,

Um, that was really freaky, very scary, you know to just sort of wake up and, ... the eyebrows sort of went quite quickly and the eyelashes went very quickly as well and, um yeah, that was just freaky. Like, you don't look right. There's something wrong there and, yeah, very bizarre and then, (pause) yeah, it was, yeah and quite bizarre that the leg hairs never grew back and the arm hairs just weren't there and oh just, ... perturbing, I suppose.

In another example demonstrating unfamiliarity, Lucy described her mastectomy, saying,

I'm more conscious of you know breasts sort of balance out the rest of you

Yeah

So to me they've been really, um so yeah, having the one breast is a bit weird.

In both of these examples, the body does not look or *feel* 'right', and subsequent positioning of the body becomes unsettled. Each of the body changes described are experienced in contrast to the body before cancer, when normative experience such as balance, symmetry and body hair are likely not to have been noticed, or may have been noticed, in the case of leg, underarm, and pubic hair, but then removed. As suggested by Williams (1996), it is only when normative bodily experiences are lost or disrupted by illness that their role in signifying 'normality' is made aware. As an implication, these descriptions of the body indicate a difficulty positioning the cancer-afflicted body within legitimate and socially recognisable subject positions.

In order to position their bodies as abject the women used metaphors. The metaphors used by the women tended to symbolise bodies that were undesirable, repulsive, and subversive of normality, contrasting with constructions of ideal femininity. Metaphors used to describe the 'self' included references to animals, such as a "silver baron ape" (Sonia), a "heifer" cow (Anna), or a "pig" (Marie); the cartoon character "Homer Simpson" (Sonia); the Muppets' character "Miss Piggy" (June); and the moon (Marie). For example, Sonia described her body, saying:

And I've now kind of look like Homer Simpson with a tummy and no breasts so it's quite an interesting, body change Yeah

Um given that I've put so much weight on with all the treatment too that's been, quite interesting.

Anna used the following metaphor to refer to her body after gaining weight post-cancer.

... everyone, apart from my very close family no one sees the difference in my body and they all go, 'What are you talking about? You're not fat at all.' And I'm like, 'Oh, I'm a frickin' heifer,' but I dress nicely so you can't see it. So that's quite disturbing sometimes. You're like, 'Why can't you understand my frustration?'

And finally, Marie used the following images to describe her appearance during chemotherapy and hair loss.

And because I was on- because I was allergic to the chemo I was on so many steroids, like so many steroids and I blew up like the biggest fattest pig like you've never seen, like big, like big, moon face. So you've got this big moon face with no eyebrows, no eyelashes, look like a freak no hair and scarf on your head (laughs softly).

The metaphors used by the women to describe their bodies tended to be animalistic, grotesque, symbolic of excess, and alien to the 'self'. Not only do these metaphors function to separate the women's bodies from more desirable discourses of embodied femininity, they symbolise bodies that are out of control, non-human, and repulsive. Further, in contrast to the prior examples

discussed, in these examples, the women are taking up the metaphors as symbolic of their bodily states, collapsing the abject body into the women's subjectivity. Consequently, the abject has implications for the subjectivity of the women as long as it remains identified as part of the body. In these constructions of the repulsive abject body, the 'abject' is something that the women attempt to distance themselves from, although not entirely with success.

## Outside the feminine body.

For many of the women, cancer resulted in a loss, or threat to embodied signifiers of femininity. Body parts and appearances positioned as 'sexual' and 'desirable' to heterosexual men tended to signify 'femininity' in the women's accounts. For most of the women, cancer had resulted in body changes that were often referred to as "ugly", "unattractive", and "old", in contrast to idealised discourses of feminine youth and beauty. Further to this, body changes due to cancer also disrupted embodied practices of femininity. The women subsequently tended to position their bodies in terms of a loss of femininity, as repulsive, and as outside the male gaze. For example, June talked about the loss of embodied sexuality following the loss of her breast, saying,

Because even though you know you're wearing a bra, naturally if you lean over a little bit, well you've lost your line, you just haven't got a cleavage anymore (pause) and that is a big thing because you know its

sexual thing, and you just haven't got that, so you have to wear higher necked t-shirts, and you can't wear v-necks and this sort of thing.

Anna positioned her lack of femininity as ambiguous after experiencing weight gain and menopause, saying,

I feel very different and it's not the feeling of, you know, every now and then you still feel 17 and you put on some mascara and pretty skirt and you're like, 'Oh, I look like a girl. Yay, that's nice,' but for more of the everyday living life there's just sort of no distinction between being a female or not being or female or if it makes any difference or it's, yeah, very bizarre obviously.

In both of these examples, June and Anna report a difference in their embodied experience of being feminine and sexual after cancer. In June's case, this was the loss of a signifier of female sexuality, the breast, and for Anna, an ambiguous positioning of her body as lacking a distinction between female or non-female. The corporeality of the body, as something that is able to be disfigured, diseased, scarred, and defiled, is usually repressed by practices and constructions of femininity that contain and regulate the body (Bordo, 2003; Zita, 1998). In other words, the corporeality of the body as affected by cancer, exposed aspects of the body and bodily functioning that are often repressed, and challenged the positioning of the body in relation to idealised femininity.

Body changes that were positioned by the women as abject following cancer challenged the ability of the women to take up subject positions aligned

with discursive constructions of feminine beauty and sexuality, as a result of the body being positioned as unattractive and ugly. 'Beauty' was signified by bodies that are thin and breasted, with smooth young skin that was free of flaws, such as marks, differences in pigmentation, and scarring (Bartky, 1988; Bordo, 2003). 'Ideal' feminine bodies were constructed in a few of the women's accounts as 'bikini bodies', that is, bodies that could be confidently displayed in public, signifying sex and feminine beauty (Bordo, 2003). These women contrasted their bodies post-cancer with 'bikini bodies' in order to position their bodies as removed from a desirable idealised feminine body. For example, Gwyn said:

Um, you know prior to all of this happening I was pretty neat and trim and could still get away with wearing a bikini and I'd never wear a bikini now as as e- (pause) as much as anything the um added weight and combined with the scar it looks like I have a butt on my front (laughs). And so (laughs) not very happy about that.

Another woman, Joanna, described a continuum between beauty and ugliness, when referring to the discolouration of her skin around her groin from radiation treatment, saying:

I'm a pretty average looking person not stunning beautiful not ugly but it's one of those things that's made me um more towards the unattractive (pause)

Yeah

Slant. So oh god I don't have heaps of things going for me I just don't need one more thing making me, unattractive (laughs).

Yeah yeah. Yeeeah

Yeah, it's pretty ugly.

The loss of feminine beauty was positioned by Gwyn as making her "feel crappy", and by other women in terms of a loss of confidence. To be less beautiful, was to be feel less sexually attractive, and often, to feel less empowerment in social situations. As such, the loss of feminine beauty signalled a loss in subjectivity for the women. In a cultural context where women tend to be defined through bodily appearances (Bordo, 2003; Fredrickson & Roberts, 1997), the loss of feminine beauty signalled a loss of subjectivity for the women, positioning their bodies as being of less value.

The loss of the feminine body also signalled a move towards invisibility within the male gaze, in the women's accounts. Experiences of the feeling of being less sexually desirable to men were reported both in social interactions, and as internalised by the women. For example, Gwyn said,

I was always um, (pause) you know all the way since I was about twelve when I became aware of, that I had a, powerful sensuality and that men were um drawn to me an- (pause) w- as I um have gone through this this sort of little journey um, it- (pause) I had to rely more on, thinking myself more as a whole person as opposed to just a very, sensual person (soft laugh), um if that if that makes sense? Um (pause) And you know I must admit I do now that I've put on so much weight

and I've I- I don't, feel sexy, or well as sexy any more. I'm aware that you know whereas before, I could um (pause) you know talk, talk to men and there would always be that spark in their eyes that's gone now so (laughs). Um, I am aware that either I've changed, in the way that I deal with people or perhaps I don't exude that that same sensuality that I used to so. Mm, there's a definite change there.

In this extract, Gwyn reports experiencing a changed perception of her body in her interactions with men, having previously positioned her subjectivity within the male gaze, Gwyn said she felt less "sexy" and now received less sexual interest from men. Subsequently, Gwyn reports a diminished sense of power in such interactions and a loss of her sense of 'self', having to draw on other parts of her 'self' to now engage men in social situations. In another example, June reports feeling conscious of her mastectomy in a possible scenario that would evoke the male gaze, saying,

Yeah. You just don't feel the same person; I know that if I'm not wearing my proper bra and some strange person, some man comes, you think, 'Oh, God,' straightaway you think, 'He's going to look straight at me.' You're not shrinking from it, but you just feel, well he'll look at you and think, 'Oh, God, you're a freak,' you know it's not the sort of person that you look at and think, 'Oh, nice looking person,' or something like that. I think it definitely does affect the way that you feel.

June reports a changed feeling in her 'self' in interactions, due to a heightened consciousness of her body and imagined social judgement of her body, exposed under the male gaze. These examples demonstrate the loss of power heterosexual women can experience when less visible or invisible within the male gaze (Hine, 2011), as well as increased consciousness of the abject body as something that could become visible, disrupting the body's desirability (van der Riet, 1998; Waskul & van der Riet, 2002).

The positioning of the women's bodies outside the boundaries of idealised feminine embodiment was also demonstrated through the adoption of discourses of ageing to construct the body post-cancer. Many of the women reported feeling older as a result of their experiences with cancer, referring to embodied markers of accelerated ageing, such as, decreased mobility, increased wrinkles and dry skin, health risks relating to cancer and menopause, tiredness, fatigue, and sexual problems relating to the act of coital sex and loss of sexual desire. For example, Joanna said, "my skin seemed to look old overnight, it seemed to sag, all the elasticity went out of it", and Sofia said, "my skin is very dry and it seems a lot thinner". Subsequently, the women tended to draw on abject images of older women's bodies to construct their subjectivity. For example, Sofia said, "I feel like an old woman now", Joanna said, "I feel like an old hag", and, "I hobble around like an old lady and I'm saggy and baggy". Anna made the following comment about her experiences following cancer:

Yeah, well I suppose I went from living in a twenty three year old young woman's body to living in a 103 year old, old woman's body.

Um, not really ... I just feel like a little old lady (short exhale, laugh) who's done her time and I don't feel sexual.

In these accounts, ageing was positioned as an unequivocally negative experience, signifying asexuality and loss of attractiveness.

In many of the women's accounts, it was experiences of premature menopause, and loss of menstruation and fertility, that symbolised the loss of a youthful attractive femininity. Ten of the women reported experiencing premature menopause as a result of cancer treatment. In addition to these ten women, Sofia said she suspected she was likely to be entering menopause at the time of interview, and June and Christine reported additional, and more severe menopausal symptoms following hormonal treatments. Despite the proximity of many of the women to menopause at the time they were diagnosed, the menopausal body was positioned as a threat to the 'natural' body by many of the women, as it was a response to cancer treatment, occurred when it was not 'meant' to, and was often positioned as happening more quickly than 'naturally' occurring menopause. For example, Sofia said:

I guess, you know, all women have to face up to menopausal things but when it happens over night, that's a bit melodramatic, when it happens quickly it's 'hang on a minute, I don't know if I was quite ready for that'.

The menopausal body was positioned as abject by the women, with the symptoms of menopause serving as reminders of the usually repressed and uncontrollable corporeality of the reproductive body (Ussher, 2006). As such,

the menopausal body was positioned as a threat to femininity and sexuality by many of the women, signifying a body that was out of control, sexually undesiring and undesirable, or repulsive. For example, the following comments on the menopausal body were made:

...there's obviously issues around bone density, growing moley things with hair sprouting out of them on my face (laughs)

Yeah yeah

(laughs softly) you know, getting that whole menopausal, spread.

Marie

I would go with the menopause if it didn't make the hair grow on my face so much (laughing)... Sofia

In the examples above, the menopausal body is constructed as a body challenging to the symbolic order through uncontained hair growth, moles, and weight gain. Again, here the ageing and reproductive body exposes corporeality usually repressed within idealised constructions of femininity.

In contrast to the accounts above, some of the women also talked about body changes following cancer that they positioned as more ideally feminine than prior to cancer. These body changes included the loss of pubic, and other body hair, that was usually removed, weight loss for Robyn, and weight gain that was still within an ideal feminine positioning for Jackie. For example, in regards to the loss of her pubic hair, Joanna said,

Ummm, I have no hair left down there which is you know, probably a good thing? But it's it's that, it's that loss of (pause) I suppose sexuality, because, it's there's nothing there. And I'll never have to have a Brazilian but you know (laughs) it's not what I intended (laughingly)... Most, I think most men prefer hairless women so I should think oh well that's a bonus

Mm mm

But (laughs) it's just one of those changes I didn't exp- didn't wanna go through.

Although Joanna demonstrates some uncertainty about her loss of hair by questioning whether it is a "good thing", she also positions her loss of hair as being preferred by men. In another example, Robyn positioned her weight loss as being more ideally feminine, saying,

... well you know certainly not the best way of losing weight, however, it- it has, it's- it- I feel um, I think that had a really positive effect because it's given, you know I feel I've got a nice body shape.... And um (pause) you know I think I look good you know, and I suppose it does make me feel more, you know more sexy, more you know, even if I don't do anything about it does make me feel, so yeah that's- that's a positive. I find that quite positive, mm.

And finally, Jackie positioned her weight gain positively, saying,

An- and I love the feeling.

Yeah

And I love the look too because like before I would basically be like a skeleton with (pause) literally, um my clothes would be hanging off me and they'd be bones sticking out and what not and that's not the case anymore there's actually a bit of flesh around everything (laughing). It's nice.

For Jackie, her weight gain was positioned as "healthy" and more ideally feminine, as opposed to prior to cancer when her body had been thinner. In contrast to other positioning of body changes as abject and outside femininity, these body changes were positioned as closer approximations of more ideal forms of femininity. Not all accounts of more ideal positioning of the body were constructed with ease, as in the case of hair loss, which was unsettling for some of the women due to the loss of control.

## The out of control body.

Abject bodies were often positioned as being 'out of control' in the women's accounts. Out of control bodies were those that breached bodily boundaries and the symbolically disrupted the 'feminine' body (Bordo, 2003; Douglas, 1966), through corporeal experiences such as disfigurement, excess in body weight, seeping wounds, a stoma, or leaking excretion and urine. As part of positioning the body as out of control, the women reported being unable to exercise full agency over their bodies, in contrast to pre-cancer experiences. The women referred to these instances of loss of control over their bodies as "frustrating", "annoying", "angry", "betrayed", "let down",

"sad", "degrading", and "depressing". For example, when referring to her experiences of urinary dysfunction, Joanna said:

Yeah, just annoying, just degrading, just frustrating, because there is nothing I can do about it.

And, Gwyn said the following in regard to her experience of weight gain after cancer.

I've always felt, fit even when I was you know slightly, um overweight after having babies and all that, I still felt like I was, in control of my body. Now I don't feel like I'm in control I can sort of, (pause) a little bit angry with my body that it let me down (laughs) you know? I was doing all the right things and then it decided to be naughty anyway.

Lucy spoke about her unhealing mastectomy wound and lack of health, saying,

...I just feel, you know, that I've lost control. I've no faith in my body, I've just lost confidence, it doesn't do anything for me.

The out of control body created a bind in the positioning of subjectivity for most of the women. According to Kristeva (1982), the abject is the primal object of repression and represents the maternal body. The maternal body symbolises corporeal states necessary for existence that are repressed in order to take up subjectivity within the symbolic order. In this vein, many of the women attempted to distance themselves from their bodies as something 'other' to them. However, at the same time, the women were not entirely able

to distance their subjectivity from their bodies due to the implications the abject body had for their subjectivities, including the moral implications associated with abject bodies.

Bodily events that breach social norms through lack of control are not considered a socially acceptable part of adulthood, and signify a loss control over the body and independence. As such, Sonia, Sofia and Anna referred to their bodily experiences using images that signified a loss of independence and child-like state. For example, Sonia said the following:

... it disconnects all your brain signals so you wet yourself when you go through chemo

Yeah

Cause you're like a child.

Sofia referred to an experience with her ileostomy, saying,

It's ah, pretty gross.

Yeah yeah

I mean I remember days, when I would, like, I had gone over to his place, and um let myself in

Mm

And um, for some reason I was really tired probably because of the chemo and I had gone to sleep on the couch and then I'd got up, and I

wear contact lenses and without my contact lenses I'm as blind as a bat, I'd just gone to the loo and managed to do something strange with my fingernails and open my bag and have it spill all over the floor, and that's not a nice thing to do in you know, your partner's house.

#### Mm mm mm

And he came home and I had no clothes and I was just sitting there, um in tears thinking 'help me'.

In both of these extracts, loss of control is linked with a state of helplessness and dependence reminiscent of childhood. Kristeva (1982) refers to the initial socialisation of the subject's body through the maternal body, in which the subject is socialised into the binary ordering of the body, such as being clean and unclean. The breach of bodily boundaries, through experiences that defile the body, such as excretion, is reminiscent of this early stage in development and prompts the women to recall a state of helplessness. Such a state is distanced from those associated with idealised, traditional and romantic forms of femininity, where the corporeality of the body remains repressed, contained, private, and outside the public gaze (Ussher, 2006).

The out of control body signified a breach of public/private binary discourses of embodiment (Waskul & van der Riet, 2002). In the women's accounts, many examples were given of abject bodies disrupting social norms of body functioning and appearances, and forcing previously private bodily experiences into a broader regulatory social gaze. Such bodily experiences are usually repressed and retained within the private realm through bodily rituals

and practices, such as those used to maintain hygiene and produce forms of idealised feminine bodies. The abject body disrupted bodily rituals and signalled problematic moral consequences for many of the women, as well as self-consciousness and shame. For example, Lucy said the following about experiencing the exposure of her mastectomy scar in public.

Um, well I was just realising I was just wearing you know a little black dress and I realised when I got home that when I turned around you could see my mastectomy scar... And I just thought you know they're actually being faced with this scar and then I get treated as ah you know, as 'the scar'

Yeah?

Or treated as a ah, person whose got um health issues.... You know I mean I had lots of you know kindness, but um, at one level, but also it's a lot of fear.

Due to the public gaze towards her body, Lucy reports experiencing a changed social positioning where her subjectivity was reduced to the scar symbolic of her illness.

The regulatory social gaze that the women's bodies were subjected to was experienced both within social interactions, and as internalised by the women in their accounts. The social gaze functioned to reflect back to the women their subjectivity as 'abject', 'abnormal' and 'ugly' bodies. Accounts of being subjected to the gaze in social situations included the following example from Sonia.

... not even three weeks ago a- a- ah- I- I- I some bloke walked past me and said 'Oh you're too fat to be on the street' (inhales) and I said 'Well you're too fucken ugly to be out'

(Exhale, inhale - shock)

And he went to say something to me and his wife was with him and I said 'Well, you know, I've had cancer lovey' she just kicked the shit out of him.

In other examples, a number of the women reported instances where they were questioned about body changes due to the curiosity of strangers seeking explanations for particular 'unusual' or strange aspects of their bodies. For example, Eva recounted an instance where she was asked for an explanation for the scars on her neck.

... a while ago when I was at work a woman, um saw it in the bathroom, she's like 'Ugh, what's wrong with your neck?', and I'm like, 'I had-', she's like, 'Do you have a rash?', I was like 'No, I had surgery'. She was like 'Oh', and then just, she didn't say anything else.

The abject body thus evoked instances of both public curiosity and repulsion, which can lead to women experiencing exposure and vulnerability. Sonia was subjected to a regulatory gaze, which deemed her body unfeminine and illegitimate for not being ideally slim. Eva's account demonstrates the difficulty of the public gaze applying meaning to abject bodies, seeking an explanation for a body that is difficult to understand through dominant cultural discourses of health and beauty. Both Sonia and Eva provide their response to

the strangers' accounts of their abject bodies, as occurring as the result of a medical condition, legitimising the positioning of their bodies as out of their control. These women did not have control over how their bodies were positioned by others in public, and thus had their bodies 'read' and subjected to the regulation of culturally dominant discourses of femininity. These instances of public interactions over the abject body reflected social perceptions of the women's embodied subjectivity, in which their bodies were made visible, separated out from 'normality', and stigmatised for appearing unfeminine, difficult to explain, and repulsive.

As part of the evidence of the internalisation of the regulatory social gaze, including the male gaze, most of the women reported instances of heightened consciousness of their bodies in public, and were careful to monitor the parts of their bodies viewed by the public, with many of the women reporting instances of feeling anxious about body abnormalities and dysfunctions, particularly bowel and urinary dysfunction. Examples of this in the women's accounts included the following two comments from June. The first extract is in regard to menopausal symptoms, and the second is in regard to her mastectomy.

... all of a sudden you're sitting there and you get these terrible hot flushes, and they're the worst thing; they're a prickly hot flush. And as I said, your face lights up and that makes you feel, 'Is everybody staring at me?'

You still feel, deep down after all this time, you still feel it's very very ugly, and you don't want people looking down there.

June's account demonstrates a wish for her body to remain private, to not gain unwanted attention, and remain invisible to the social gaze. Further, her account of menopausal symptoms reflects broader social discourses of the menopausal body as abject, in which women report feeling embarrassment at instances in which the menopausal body became visible in social situations (Hunter & O'Dea, 1997). In another example, Sofia said the following about her feelings around social perceptions of rectal cancer.

But [I] imagine a lot of the people, oh I mean around the office that were hearing it were like 'Oh ughhh', you know, 'How'd she get that?' (laughs softly). And then if they had more information and knew that it was rectal cancer, 'Ewww'.

Mm

It makes you feel like the unclean.

Sofia's comment reflects a social construction of cancers relating to bowel dysfunction and excretion, as abject. The internalisation of her body as abject has implications for her subjectivity; she reports feeling separated from others, with her herself becoming the 'unclean' from cancer. The regulatory social gaze served to reflect back to the women social constructions of their bodies as 'ugly', 'abnormal', 'repulsive', and difficult to place within available and legitimate social meanings. This was particularly the case where body appearances and functioning did not signify the presence of cancer in a

socially acceptable way, but a body that was out of control, subverting the discursive structures used to make meaning of embodiment.

The out of control body and the regulatory social gaze of such bodies had moral implications for the subjectivity of the women. Abject body changes, such as weight gain, signified feminine excess, which had implications for the way the women positioned their subjectivity in relation to the moral consequences such embodied signification raises for women, including a lack of self-control (Malson, 1998). Self-control is a socially valued characteristic of idealised femininity, with lack of self-control signifying failure and laziness (Chrisler, 2008). For example, Sonia made a comment about her weight gain after cancer in response to the following question:

So how have you felt about the change in your body shape

Oh crap (laughs)

Yeah

Really frustrating, really frustrating. Because a lot, ah, especially when the hair grows back and you hear the socio-cultural comments of 'oh, you're very fat, why don't you go on a diet, have you thought about Jenny Craig, have you thought about this', and I just look at people and say 'I've had cancer, fuck off'.

Within this extract, Sonia demonstrates that without other bodily signifiers of cancer present, such as the loss of hair or presence of a headscarf, weight gain

was constructed within a broader social gaze that regulates larger women. Within this gaze, it is not okay for women to have large bodies, and thus to avoid being positioned as undisciplined in maintaining bodily sizes, women must be seen to be actively doing something about their bodies, specifically diet and exercise (Bordo, 2003). Further, it is not acceptable to embrace such a body, but socially acceptable to take up a struggle with one's body, and express dissatisfaction and loathing towards it. In the extract above, Sonia defiantly resists her positioning as a larger woman within her socio-cultural context and positions her weight gain as occurring due to cancer, confronting the stigma around larger women's bodies and resisting regulatory practices to control to her body. Experiences and constructions of the abject body in the women's accounts were subsequently underlined by tensions between subject positions in which the women took up and resisted the abject body.

## Taking up the Abject Body

## Failure and self-blame.

The women constructed their sense of 'self' in relation to the abject body, reporting different experiences of 'self' according to whether they aligned or distanced their subjectivity from the abject body. Many of the women took up the abject body as a subject position in their accounts. In doing so, the women positioned themselves as having failed to prevent, maintain, or contain the abject, and were not only reminded of the corporeality of the abject body, but also adopted a positioning of the abject as within the 'self'. In such examples, the abject body signifies 'repulsive' character traits

that are not socially valued and threatening to the symbolic order, including a lack of morality, self-control, or the absence of rituals that properly separate the clean from the unclean, and public bodies from private bodies (Douglas, 1966). For example, Sonia said that she was "absolutely disgusted with herself" following her weight gain, and, "it's more me (higher pitch) more frustrated at me. Cause I want it now. I want my figure and my body back now", while Sofia said, "I'm really worried about what kind of person, as far as toileting goes, will I be from now on". In another example, Gwyn said the following:

So, um (pause) I feel like I- I'm not doing enough at the moment to, to um, help myself. So um, that leaves me a bit frustrated and you know I said I- I'm not beating myself up about it, but I'm certainly conscious of it an- and not very happy with the effort that I'm putting in.

These examples demonstrate 'repulsion', or in at least in Gwyn's case, possibly ambivalence, of the women towards their 'selves' and their lack of ability to exercise mind over the body. The fragility of the women's subjectivity is also demonstrated in these examples, as cancer exposes the corporeality and uncontrollability of the women's bodies.

Examples of failure to contain the abject body in the women's accounts also included descriptions of failures to perform body practices consistent with the production of idealised femininity. Bodily practices structured around idealised femininity are those that separated women from the positioning of the corporeality of the women's bodies as abject, both

containing and maintaining a body that is clean, proper, and controlled (Ussher, 2006). Such embodied practices also serve to provide a sense of continuity in feminine identity (Butler, 1993). In the following extract, Joanna describes the disruption to her feminine bodily practices following cancer.

Umm, (pause) (exhales) oh as I said I just don't feel very attractive.

Um I yeeeah, emotionally it's pretty (pause) confronting, maybe?

Umm, just I think it's just lacked a bit of confidence because yeah I don't I don't seem to spend much time looking after me anymore because it's really not worth it. As in- as in appearance wise.

Um, I can't remember the last time I shaved my legs and that's really bad. And I know it's only superficial stuff,

Mm

But it's that care factor I think. Um, and yes it's been winter too but, you know, it's pretty gross.

Joanna refers to being "confront[ed]" by the abject corporeality of her body, saying that taking up hair removal practices associated with the production of an attractive feminine body is not "worth it" in her current state of bodily abjection and absence of attractiveness. By not maintaining bodily practices that produce clean, proper, and controlled forms of femininity, the abject corporeality of women's bodies are further exposed and positioned as repulsive. Disruptions of feminine bodily practices by the women were often described as contributing to a possibility of failure on behalf of the self, leading to the positioning of the women's bodies in terms of a loss of

femininity, as lacking in sexual desirability and attractiveness, and as repulsive. The failure to maintain feminine bodily practices also exposed the fragility of idealised forms of femininity, as states of abjection reminded the women of a difficulty performing an attractive feminine subjectivity (Butler, 1993).

Many of the women took up a discourse of individual responsibility for health to construct their failure to control, and their attempts to regain control, over their abject bodies. Discourses of individualism overemphasised personal responsibility and ability to control outcomes (Lafrance, 2009), while women were often still struggling with long-term effects of cancer, such as fatigue. Within this subject positioning, the abject body signified the presence of disease, absence of a full recovery to health, or a return to having control over the body. Embodied discourses of femininity were also present in this construction, as 'thin', 'fit' and 'attractive' bodies signified a 'healthy' body (Bordo, 2003). By taking up discourses of health, the women positioned themselves as individually responsible and in control over their health outcomes, including possibilities for remission and weight loss, as demonstrated in the following quote from Gwyn:

I know that I can, um, affect my health and get myself back down to a reasonable sort of a um, a weight and level of fitness. And I refuse to beat myself up in the meantime because I'm not there yet, it's only been a year since I finished treatment and um you know the- the- tiredness is really there. And then on the other hand there are studies that show that people who exercise um have better outcomes with

cancer not returning, so I'm like paranoid on that front that I'm not doing enough to to prevent it coming back. But then I did everything beforehand and I got it in the first place so (laughs)

Yeah

You know, you can't win (laughs).

The abject body provided a tenuous bind for the women where they often struggled to control their health and illness, as well as control bodily signifiers of health and feminine attractiveness through bodily practices. These discourses positioned the women's health as an individual issue, separate from wider social pressures of femininity, or the corporeality of cancer. In other words, some of the women reported desiring thinner, fitter and more attractive bodies for their own health outcomes and wellbeing, rather than because they were under pressure to conform to the social pressures of femininity (Tischner & Malson, 2011). Such discourses function to separate the individual from society, positioning health as an individual moral lifestyle issue, separate from the impact of wider cultural and socio-political discourses on women's wellbeing (Lafrance, 2009; Ussher, 2011).

Within the accounts of failure to contain the abject body, the women not only positioned themselves as responsible for their bodies, but also as needing to negotiate the conflicting moral territory created by the existence of the abject body. In negotiating the moral territory and maintaining a sense of agency, the women often positioned themselves as both to blame *and* also unable to fully control their bodies, abdicating full responsibility and often

defending themselves from subject positions that implied moral deficits, such as being lazy or lacking in self-control (Chrisler, 2008). For example, in the following extract, Sonia takes up a position of self-failure, while also defending herself against the moral deficits socially signified by weight gain, saying,

I feel like I've let myself down. I know it sounds bizarre. But um, given that everything I've had to fight, and what have you but, and I look at it proactively I've got to give myself some breathing space it's not like I've been on the on the couch for- for three years eating bon bons everyday, or cream cakes everyday, or watching television twenty four seven. It's not like I've been that. Some of them- when- the logical side of my brain is saying 'It'll come, it'll take time, it'll take time', the other side of my brain is going 'Yeah hurry up, hurry up, hurry up'... I'm my hardest, I'm my worst enemy.

Sonia wrestles between her failure to control her weight gain, and abdicating herself of social judgements, distancing her subjectivity from a position that may suggest she lacks self-control with food consumption and exercise. These accounts were reminiscent of instances of 'tightrope talk' as discussed by McKenzie-Mohr and Lafrance (2011), where women construct complex accounts of their subjectivity using "both/and" rather than "either/or" to avoid binary positions and recognise themselves as both having agency *and* avoiding self-blame (p. 61). In this case the women positioned themselves as *both* responsible for loosing weight *and* also not to blame for gaining weight due to cancer.

#### Shame.

As noted previously, abject subject positions were not without unease and fragility of subjectivity. Many of the women reported emotional narratives and embodied descriptions suggesting they were experiencing shame around their bodily states. Shame as an affective state is often not directly reported in interview interactions, but implied through descriptions of experiences and the fragmentation of meanings in talk (Jones, 2003). Jones positions shame as a "private and intimate emotion" brought by the "feeling of being judged by a real or imagined other" (2003, p. 61). As such, shame can be viewed as often repressed in social interactions, though visible through fragmentations of meanings. In the women's accounts, there were also examples of embodied actions that were indicative of feelings of shame, in which the women separated their bodies from the view of others. For example, Christine said,

Up til couple of weeks ago I'd get dressed in the bathroom if I was at his place, I have got dressed now, or changed for bed in the bedroom, but my back's totally turned and I, and I sort of freeze up if he walks in at that same time, still.

## And, Joanna said,

Um, I don't know maybe I am a bit concerned about a bit of rejection that ugghhhh yeah yeeeeah cause I do get quite tense if yeah if anything he does try and get a little bit intimate I do get quite tense.

Both of these examples are demonstrative of the women separating their bodies from the sight or touch of their partners, with Joanna pre-empting the possibility of her partner acting with repulsion and rejecting her body.

Many of the women constructed the abject body as threatening their subjectivity if visible, particularly to others. For example, in the following extract, Holly describes her experience of hair loss during chemotherapy.

But then with my second round of chemo it was like 'Yeah, all your hair's going to fall out now'. But, um it didn't really all fall out, I still had like, wispy bits of it and I just never shaved it and it was horrible and I hate looking at photos of it.

Yeah?

I looked like a pale, like, gross person (laughs) with not much hair.

In this extract, Holly describes her own difficulty identifying with images of her self while experiencing hair loss due to cancer treatment. Further, she distances her own subjectivity from this image by saying she "hate[s]" seeing photos of herself, and compares her image to that of a more generalizable, but repulsive, "gross person", rather than an image that could be taken up as familiar and identifiable, or even attractive. In another example, Sonia also describes her experiences of her hair loss following chemotherapy.

Just ah i- wasn't a real good thing and I would walk along and clumps would fall out and um it was just really not nice and I thought it was quite disgusting so ah I- I waited till my husband got home, that

evening and said 'Look I'm going to get in the shower and I want you to shave whatever remaining hair I have off left because it's just too messy there's hair everywhere and I don't like this falling out you know. Yo- you have seen the Hiroshima (inhale) and that kind of horrible stuff and it's not a- I don't want to, expose people to that. I mean I was appalled at it and I didn't want other people to be appalled at it.

In this extract, Sonia distances her subjectivity from her body by adopting a position where she is repelled by her hair loss, saying it "wasn't a real good thing", and she "thought it was quite disgusting". To illustrate the level of horror of her hair loss she makes a comparison to an image of the traumatic aftermath of a nuclear bomb on human bodies, evoking both physical and psychological trauma. Sonia then takes up a position of protecting herself and others from abject trauma, separating herself and others literally from the abject, by removing it from her body and shaving her head to prevent further trauma to both herself and any others who may witness it. In these examples, the women position their bodies as abject, and indicate a discomfort with their bodies and separating them from the view of others, suggesting that the abject body is connected to experiences of shame.

## Managing and Resisting the Abject Body

#### Concealment.

There was an uneasy relationship for many of the women with their bodies, not only reporting instances of taking up the abject body in their

accounts, but also distancing their subjectivity from the abject. Many of the women engaged in a range of bodily practices and employed the use of accessories that were designed to conceal the abject body. By concealing the abject body, women were able to restore a more idealised feminine appearance, avoid the regulatory social gaze, and regain a sense of control over their bodies. Bodily practices were performed to conceal abject body changes that had become, or were at risk of becoming, visible, and included the use of clothing and accessories, make-up, hairstyles, prostheses, wigs, scarves, diet, and exercise. For example, Jackie described the assistance she received from a woman of the organisation 'Look Good, Feel Better', saying:

... she actually came to my house and brought all this make-up and what not, and we went through putting it all on and how to keep it subtle and so forth

#### Mm mm

So, that was good, that was really good (pause). So, so yeah no it-(pause) you've just got to adjust... and that's what it's all about.

Both June and Robyn described employing the assistance of hairdressers to develop new hairstyles suited to the different ways their hair had grown back after chemotherapy, with Robyn saying,

... my hair is still a bit, I am still a bit conscious of it because it's still a bit, it's not the same, as it was, before. Um, it's not as sort of thick and um there are gaps. And the hairdresser's very good, she kind of (pause) does a style that sort of suits it, spikes it up, and makes me feel good.

Finally, some of the women also talked about using clothing to avoid being positioned as ugly or sick, as Sofia said, "when I went through radio[therapy] and wanted to dress up and not be one of the sick people". Sofia's comment is suggestive of the adoption of bodily practices to avoid being positioned outside social norms of health and therefore risking being positioned as 'other'. In an example of using clothing to avoid being positioned as unattractive or ugly following weight gain, Gwyn said,

... probably the best thing I did to help cope with the changes is (pause) I took out a bunch books from just the public library on image and um image makeover and that sort of thing. Because I've got a very different body shape than what I've always had to dress. So I've gone through my wardrobe and you know um toss a bunch of things out that don't fit any more and, tried to make conscious decisions on what to purchase so I could look the best that I can, in *this* particular shape and I think it's worked quite well because I've had quite a lot of compliments over the last couple of weeks so (laughs) so that's one very positive thing that I did, that's helped a lot...

In these accounts, the abject body is concealed and idealised feminine appearances restored through body practices that enabled the women to avoid being positioned as 'ugly' or 'sick'. In the examples above, the women also talked about feeling good, or having more confidence, suggesting that the appearance of the body, managed through the concealment of the abject, was closely linked to the women's subjectivity. Positive comments from others

helped with this process, including comments from friends, family, and work colleagues. For example, Robyn said,

And [friends and family] often said you know 'We like, you know, the new hairstyle' and um (pause) that it that I have sort of been sprouting um, which is again it's made it much more comfortable to have, even though I'm aware it's still quite thin, it, the fact that you get some positive comments it certainly makes you less conscious of it.

Receiving comments from other people reinforced a feminine subjectivity for the women by providing a reflection of an attractive feminine appearance.

A number of women also reported employing accessories and clothing to conceal their bodies to avoid experiences of being asked to explain their bodies to members of the public, or having members of the public respond to their bodies with repulsion. For example, in regard to her scars, Eva said,

Um, I think (pause) well wearing necklaces and scarves and stuff. Um but that's sort of covering it up... it's just those few occasions, which possibly now wouldn't affect me as much, but when someone's sort of, horrified to see them, and it's for that reason that I cover them up.

In another example, Holly said,

I didn't buy low cut things my tubes would fall out of, I suppose.

Yeah

But like at the same time I really didn't care, it was more just that like I just got sick of explaining it to people.

Both Holly and Eva talked about using clothing and accessories for the purpose of concealing their bodies to avoid the social positioning of their bodies as abnormal, confronting, or deserving of public curiosity, all of which are asexual and unfeminine subject positions. Such practices also allowed some control over how their bodies appeared in public, returning the abject body to the private realm and avoiding stigma due to cancer. These practices did not challenge hegemonic discursive constructions of feminine beauty, and can be seen as contributing to the reproduction of such discourses. Such bodily practices can be seen as established feminine cultural rituals undertaken to contain abject or unfeminine bodies from the gaze of others. In the women's accounts, these bodily practices and rituals were used and adjusted to account for the effects of cancer and conceal abject body changes so that a body positioned as feminine and attractive could be restored.

A few women talked about employing bodily practices that were positioned as part of regaining control over their bodies, particularly with regard to weight loss through diet and exercise. For many of these women, regaining a sense of control was part of exercising some agency over their bodies, and avoiding the abject positioning of their bodies, with the hope of getting back to a more 'attractive' body in the future. For example, Eva said,

I've also joined a gym so I think that helps. I basically haven't done, any exercise (short laugh) for the last two years.

Yeah, yeah.

Um, so that's really helpful as well, it's good for stress and, everything. Um, and I- yeah I just feel more in control and more capable of, um making decisions for the long term and stuff like that.

In addition, Anna said,

Very slowly, I'm starting to lose a little bit of weight and slowly starting to see little changes in my body shape which is nice, but I'm working very hard and getting very little results for that but the little changes are there... I mean, that would have been 18 months after I finished treatment that I finally started doing some exercise and that felt really good, you know, taking control.

Both of these examples demonstrate advantages for the women in regaining control over the body through exercise including increased fitness, energy, and weight loss. Eva's comment particularly demonstrates a social construction around weight and femininity, where having control over one's body also symbolises having control over one's life (Bordo, 2003; Malson, 1998; Zita, 1998). In Eva's case, part of regaining control was allowing her to start to make decisions about her future that she had not been able to make previously. It is also likely that by regaining control over the body through diet and exercise the women were better able to avoid moral social positioning of their subjectivities, such as assumptions weight gain was the result of a lack of self-control (Chrisler, 2008).

The women's accounts of adopting bodily practices of concealment were not without tensions and difficulties, due to an ongoing risk of visibility within the social gaze, physical discomfort, and at times, the inadequacy of particular practices of concealment. For example, some of the women reported experiencing discomfort adjusting to prostheses, as shown in the following comment from June:

... because all of a sudden you've got this great big weight hanging down in your bra, and they're different when you've got your own breast in there.

# Similarly, Lucy said:

...to wear it, um, well because my wound hasn't healed, so to me was heavy and a- also before all this I had never worn a bra... the prosthesis I still can't get my head around. And I've got the foam one and the silicon one and neither of them an- and cotton ones. And I can't get comfortable with them.

A couple of women who had experienced significant weight gain following cancer reported feeling frustration at the lack of clothing available for their bodies, particularly when other conditions were taken into account, such as skin sensitivities, or the loss of a 'feminine' shape due to mastectomies. As Anna said,

... it's really hard now, to find clothes that fit nicely. And so that's, that's quite depressing at times.

And, Sonia said,

... sometimes the clothing isn't made for women without breasts

Yeah

Unless you buy men's clothing and th- there isn't any clothing out there for women who have had a mastectomy.

Finally, a few women reported some forms of concealment as inadequate, meaning that the women remained at risk of revealing, or being unable to fully contain, the abject body. For example, Sofia said,

... they have a help pamphlet that tells you about sex and having an ileostomy and they tell you that you can wear crotch-less undies

Mm

And that should fix it. And it's like 'no' because I've still got this thing on me, that just doesn't, it's gross.

Tensions and difficulties with concealment meant that the women remained conscious of their bodies as being at risk, and vulnerable to the social gaze. Further, practices of concealment reveal an ongoing struggle to maintain control and manage the abject.

## Resisting embodied discourses of feminine beauty.

Some of the women exercised agency over their abject bodies by adopting subject positions within their accounts that resisted discourses of

idealised feminine beauty. Positions of resistance were taken up through embodied actions that countered the social regulatory gaze, through rejecting the cultural imperative of feminine attractiveness and containment of the abject body, confronting the social gaze, not caring about body changes, or positioning other priorities, such as survival and the functionality of the body, over aesthetic appearance. Across the sample, some women were more likely to take up this subject positioning than others, depending on the extent to which they tended to draw on cultural discourses of idealised femininity to construct their own subjectivity. However, women who resisted idealised femininity also did not completely separate their subjectivity from discourses of the feminine body.

Sonia and Philippa specifically talked about refusing to adopt bodily practices of concealment as a rejection of the social pressures to conform to embodied discourses of femininity, involving rituals that conceal the abject body from the regulatory social gaze. In refusing to take up feminine bodily practices and contain the abject body, both Sonia and Philippa allowed their bodies to be seen, often in public. For example, Sonia said,

And the Look Good Feel Good was just to me a red flag to a bull.

Because I think you should take a person as who they are regardless of race, colour, what they look like, who they are, religion, and I have no time for that, that ah, that falling into the aesthetic. And especially when they kept pushing on me about having a wig, and you know um, and if you don't have hair you somehow are an abnormality, in society

Mm

And that was really quite frustrating.

Mm

Which was probably why I made the conscious decision half way through chemo (laughs) I'd lost my hair going nah, not going to do it, sorry.

Sonia expressed anger at discourses of feminine beauty, positioning them as oppressive, and constructing her subjectivity as that of primarily, an "individual" and a "professional" woman, positions that were constructed as more important than 'surface' aesthetic appearances. In another example, Philippa said the following about her experiences of hair loss following chemotherapy treatment:

Well as I said, treating it as a bit of a novelty was part of the whole adventure. And not overly wedded to I've got to look a certain way to be socially acceptable or something like that. And also just not wanting to get unnecessarily burdened by worries about things that can't be changed. My hair was going so.

How did you find, because did you lose your eyebrows and eyelashes?

Yeah that was good.

It was good?

Yeah that was fun.

And, in another example, Philippa said,

Well not caring would be a start like um, I'd say, "Oh well this is just how I look at the moment." You know I'd go out with a headscarf and looking a bit fat and whatever and that's just whatever.

For Philippa, rejecting a discourse of feminine beauty was part of coping with body changes that she could not control. In doing so, she positioned body changes at risk of abjection as novel, fun, and part of the "adventure" she was undertaking (Waskul & van der Riet, 2002). A few women took up subject positions that directly confronted the regulatory social gaze, refusing to self-regulate their bodies by letting their abject bodies be seen by others, allowing others to experience shock and horror at their bodies, position the women as having cancer, and, at times, confront sexist regulation of their bodies.

Examples of confronting the social gaze included the following from Holly:

I did um, like, cause I like cause I still had my central line, for a while, and I did love wrapping that and just like wearing it out of my top and being like a robot. And-

Yeah? (Laughs)

I loved it... So yeah, so I was just at work, just working on the counter and stuff and yeah, like people would be like 'Oh, what's that?', 'Yeah, it's a central line, I just had cancer' and like 'Ohhh' (laughs).

(Laughs) How did they react?

I don't know just like shocked.

Holly positioned herself as enjoying shocking, or making members of the public uncomfortable over their curiosity about her body. She both allows the social gaze of her body with cancer, and confronts a taboo around cancer as something that is usually not directly spoken about. Other examples of confronting the social gaze included Marie, who allowed her family to see her body following cancer.

And so I thought 'Well you know, it's not my fault this has happened, it's just happened and I've just done the best that I can do to get through it, so I'm not going to be ashamed about it'... if the kids have walked in and I'm in the shower, they've walked in when I've been in the shower... So in terms of- when you've got a boy, and I particularly, I've got a boy and a girl, and you want your boy to know that women look, different all the time, and it's okay. And you want your girl to know that women look different all the time and that's okay. So it was hard sometimes but you think well they don't know any different um... it's not something that I've done that I need to be ashamed of, it's something that I've done to save my own life

Yep

And- and protect my life in the future.

By confronting the social regulatory gaze, and not conforming to the regulation of the abject body by containing it, these examples demonstrate instances of the women disrupting the social gaze and rejecting discourses of contained idealised feminine beauty (Foucault, 1980). In doing so, there are

constructions in the women's accounts of allowing something more 'real' of their bodies and experiences to be seen by others, and not participating in embodied discourses that could be seen as 'artificial' or stigmatising.

A few women resisted discourses of feminine beauty by positioning the functionality of the body as more important than aesthetic appearance. Within this subject position, feminine constructions of beauty were positioned as frivolous, having little value for everyday life, survival, or nothing to do with who the women were as individuals. For example, Sonia said the following about her experiences of hair loss:

I didn't care that I didn't have, any kind of hair there in terms of the aesthetics or the prettiness, that didn't bother me one little bit. But um I did find it really hard going not having hair, to keep cool on the head, and to stop the sun glare.

The functionality of the body was also used to justify coming to terms with body changes. For example, as part of comparing the loss of her breast, to her husband's loss of a hand, June said,

What am I moaning about, you know, you don't have to use a breast for anything.

Within this positioning, the aesthetic of the body is considered of lesser value compared to the particular functions of the body. The women employed this construction to 'let go' of body parts or changes that did not serve a function, such as breasts and ovaries, and also position the remaining functioning of the body, including healing processes and survival, as more important. Discourses

of idealised feminine beauty were also positioned as undermining the embodied construction of what it meant to be a person, where the 'inner' depth of a person is valued over their 'surface' appearance. Within this construction of embodiment, the mind is positioned as the 'real' and 'true' subject, as opposed to the body, which is not a reflection of the mind as it is unable to be controlled. The refusal to take up feminine discourses of beauty and conceal an abject body could be seen, in part, as the women creating the space that they needed to adopt coping strategies that were beneficial for their wellbeing in coping with body changes.

# Re-positioning the body through personal transformation.

A couple of women resisted constructions of the abject body by repositioning their bodies as sites of personal transformation following cancer. Body changes that were also positioned as abject at other points in these women's accounts were positioned as bodily markers signifying their journey with cancer, including their ability to overcome adversity and survive. For example, Eva, said the following about the scars on her neck:

In terms of the things that I can't change about my body, I'm happy to have them because it has meant that I am still here, so the scars and stuff. Um and now, there was something in the newspaper a while ago and there's a company in America that makes a mould that looks like your scar and it's like a charm that you wear on a necklace. So you actually wear like, you pretty much wear it as a badge of honour kind of thing. Um, but mine is already a necklace. So, um, yeah, I think mo-

probably more now it would be, um badge of honour rather than a reminder of impending doom.

In addition, Philippa said,

So it's a bit ugly down the bottom but I don't, it's a bit of a war wound and a bit of a story, a place on which you concentrate stories about the experience.

In both of these examples, scarring became a marker symbolising the cancer journey. The positioning of scarring in this way is reminiscent of cultural rituals in which the surface of the skin is inscribed, such as tattooing, where 'inner' meanings are symbolised through inscriptions on the surface of the skin (Grosz, 1994). It is likely that these experiences are not separate from discourses of embodied femininity, as for both of these women, personal transformation is something that occurs within a private individual realm, rather than something that confronts or disrupts the social gaze that regulates women's bodies. Further, as markings on the surface of the skin is resemblant of cultural practices of inscription, it is likely that such body changes are more able to be re-positioned than other abject body changes such as weight gain, for which there is a significant amount of cultural stigma attached (Chrisler, 2012; Tischner & Malson, 2011).

In another example of personal transformation through the site of the body, Holly positioned herself as feeling more confident following cancer, saying,

... like I'm heaps more comfortable in my body now so, I think I'm heaps more comfortable in front of other people.

Yeah

Yeah, but, (pause) yeah, confidence that, like, I don't know, would've taken ages for me to gain but I could just be like

Yeah, yeah

So I don't know if that's just me, because of my cancer experience, or just me growing up and having had a long term boyfriend before, um, for a while at least and so now I'm just more comfortable.

In Holly's example, the feeling of being comfortable in her body signifies greater social confidence, and the body is re-positioned as a site of personal growth, possibly due to cancer or a long-term relationship. In addition, Jackie also spoke about feeling more comfortable in her own body saying that she had less "tension" in her body, was able to be more aware of bodily sensations, and now maintained a "healthy" weight. Jackie attributed her transformation to the ending of a stressful relationship and re-prioritising of her own needs at the time of her cancer. She responded to my prompt regarding her changed bodily experience in the following extract.

You said just before that you like the feeling, what does it feel like to be in a body that you like?

Very comfortable. Um (pause) yeah, (pause) yeah comfortable and yeah just very pleasant, feel. And again it sounds so silly, I feel so

good. Um (pause) regard- regardless of what I've got. It's probably the best I have ever felt in my entire, life. And I'm fifty three, you know, so.

Like Holly, Jackie also reports "feeling" comfortable in her body after cancer, raising a discursive tension between 'feeling good in your body' while still living with the possibility of cancer. In all of the examples above, the women's bodies were positioned as the site of personal transformation. This positioning, in part, acknowledges the emotional and physical challenges that were overcome by the women in their experiences with cancer. Such discursive strategies and embodied experiences may be useful for considering different ways of positioning the body other than against cultural standards of idealised femininity, privileging the subjective *feel* of the body (Young, 2005), in addition to other coping strategies.

### **Analysis Discussion**

The women often constructed the changes to their bodies after cancer as 'abject', demonstrating difficulties making meaning and 'placing' their bodies within the symbolic order, as well as reporting experiences of horror and repulsion towards the body (Kristeva, 1982). Processes of making meaning of the body produced uneasy, fragile, and sometimes threatening implications for the women's constructions of embodied sexual subjectivity. Many of the women reported bodily experiences that challenged hegemonic discourses of embodied femininity and sexuality, and subsequently meant that the women constructed their bodies as becoming *invisible* to the male gaze,

and having less value in terms of sexual attractiveness, beauty, and discourses of idealised femininity. In addition, many of the women also reported becoming *more visible* within the regulatory social gaze due to bodies that were positioned as unfeminine, out of control and breaching of material and symbolic public/private structures of embodiment (Douglas, 1966; Kristeva, 1982; Waskul & van der Riet, 2002). Subsequently, the women accounted for abject body experiences in terms of both taking up, and managing and resisting the abject body. Accounts of taking up the abject body were characterised by descriptions of failure, self-blame and shame. Agency was exercised over the abject body by the women within accounts of managing and resisting the abject body, which included practices that reinforced discourses of feminine beauty through body practices of concealment, or resisting discursive ideals of feminine beauty, or by re-positioning the body as the site for personal transformation.

The cultural context of the women in this study is one that places significant emphasis on the sexual attractiveness of women's bodies over other aspects of embodied femininity (Bordo, 2003). Indeed, within many areas of both public and private life occupied by women, the appearance of women's bodies is prioritised in relation to discourses of feminine beauty, youth, and sexual attractiveness, including thinness (Chrisler, 2012). Considering this cultural context, the experiences reported by women in this study, of having feminine and sexual subjectivities disrupted through the abject corporeality of the cancerous body were confronting, horrifying at times, and disruptive to the women's constructions of their 'selves' as feminine and sexual. Idealised

constructions of feminine embodiment functioned as a comparison point throughout the women's accounts, illustrating the hegemonic position these discourses occupy (Bordo, 2003), and meaning that the women were left with a social positioning of their bodies as being sexually undesirable and of less value. Many of the experiences reported in these accounts have some similarity to those reported by women in relation to ageing and menopause, where women's bodies also become invisible within the male gaze and are subsequently cast as asexual and abject (Hine, 2011), requiring monitoring to repress the functioning of the body under the regulatory social gaze (Ussher, 2006). While these discourses are not uncontested by older women (e.g. Gott & Hinchliff, 2003; Jones, 2002), the cultural dominance of older and menopausal women as 'asexual' can create difficult social conditions for the women to negotiate. Further, the accounts of the abject body in this study suggest that there was a level of trauma and confrontation for the women due to the changes to their bodies from cancer.

The practices of management and resistance employed by the women to exercise agency over the body after cancer can be seen, in part, as coping strategies for dealing with the stigma that occurs around women's bodies that appear 'unfeminine' and 'abject' (Chrisler, 2012). Further, similar to other studies that have focused on women's experiences, considering the broader socio-cultural contexts of women's bodies, hegemonic discourses functioned in the women's accounts to produce individualised de-politicised accounts (McKenzie-Mohr & Lafrance, 2011; Ussher, 2011), evident through accounts of failure, self-blame and shame, indicating personal moral failure. Many of

the women in this study had to engage in considerable work to conceal the abject body, and discursively resist the social positioning of their bodies. It is important to note that practices of bodily management did require effort, including the monitoring of the body by maintaining a level of self-consciousness of the women's bodies, as they appeared to men and in broader social interactions within the regulatory gaze. As such, the discursive work engaged in by some of the women to resist discourses of feminine beauty and position their bodies outside hegemonic discourses of femininity and sexuality as 'legitimate' was significant, particularly when continuing to experience social reflections of their bodies as marginalised and stigmatised. Such accounts are important to acknowledge when considering how women make sense of their bodies in relation to idealised discourses of femininity (Ussher, 1997a), and can be seen as part of a broader feminist project of positioning women's experiences within broader cultural and socio-political contexts (Brooks, 2007).

The analysis contained in this chapter can be examined in relation to studies that have examined issues of embodiment and cancer through a conceptualisation of the material and symbolic aspects of the body as in breach of bodily boundaries (Manderson, 2005; Waskul & van der Riet, 2002). Similarly to the current analysis, accounts of the body involved a loss of control, confrontation and horror, following instances in which the boundaries of the body are breached. The current analysis extends this work by considering how experiences of the abject body related specifically to women's experiences of sexual embodiment. As noted earlier, the corporeality

of women's bodies are at risk of being positioned as 'abject', a state that is repressed in order to take up socially sanctioned feminine positions within the symbolic order (Kristeva, 1982). In addition, bodily practices that people with chronic illness engage in to manage their bodies tend to be discussed as part of producing biographical meanings and approaching the problematic ground created between body and mind in instances of the loss of bodily control (Waskul & van der Riet, 2002; Williams, 1996). Bodily practices of management discussed in this analysis were specifically gendered, and not separate from discourses of heterosexual femininity. Further, embodied discourses of idealised femininity are performed through bodily control (Chrisler, 2008), suggesting that sexual differences need to be considered in understanding the bodily management of chronic illness (Manderson, 1999).

As discussed in the literature review, many studies within psychooncology have noted impact of cancer on women's experiences of lowered or
diminished 'body image', and decreased feelings of attractiveness following
cancer (e.g. Avis et al., 2004; Beckjord & Compas, 2007; Fobair et al., 2006;
Moreira et al., 2010). The analysis contained in this chapter, extends this
work by providing an account of the corporeality of the feminine body with
cancer, and the social conditions which produce detrimental effects on
women's valuing and positioning of their bodies as 'sexual' after cancer. The
implications of this analysis can be seen to shift the positioning of 'risk' of
detrimental outcomes purely as an experience of individual women, to the
cultural discourses that actively function to marginalise women's bodies
(Blood, 2005). The positioning of the women's subjectivity in relation to the

abject body in this study was also associated with other body practices and discourses of heterosexuality that contributed to how the women positioned their sexual subjectivity, which will be examined in the following analysis chapter, 'Positioning the Body Inside and Outside 'Sex''.

# Chapter Seven: Positioning The Body Inside and Outside 'Sex'

As demonstrated in the previous two chapters, the corporeality of cancer can be seen to be disruptive to experiences of the body as 'subjective', 'feminine' and 'sexual'. This analysis chapter will examine the women's positioning of their bodies in relation to the social construction of 'sex'. Discourses of heterosexuality tend to be structured around notions of 'normality', including the structuring of heterosexual practices around coital sex (Gavey et al., 1999; McPhillips et al., 2001). It is also through the "configuration" of bodies in sexual practice that sexual subjectivity is "brought into being", with changes in sexual practice producing different subjectivities (Bryant & Schofield, 2007, p. 321). Further, 'sex' is often positioned within a discourse of 'health' as a natural and healthy part of adult life (Hyde et al., 2011), which may further marginalise women with cancer who are unable to take up practices of 'normative' heterosex due to bodily change. The women's experiences of 'sex' thus had implications for their positioning of femininity, including their roles within relational contexts (Jack, 1991; Lafrance, 2009).

Informed by dichotomous 'normative' discourses of heterosexual femininity, the women in this study positioned their bodies inside and outside 'sex', with some of the women moving between these two positions within their accounts. The analysis in this chapter will firstly consider the women's positioning of their bodies within 'sex', examining 'normative' practices of 'sex' within the theme, 'Experiencing bodily ease during sex', and the management of risk to 'normativity' within the theme, 'Managing the

dysfunctional body during sex'. Further, the relational context of the women's adoption of subject positions within 'sex' will be examined in the theme 'Positioning the body within 'sex' in the context of heterosexual relationships'. Secondly, the analysis will consider the women's positioning of their bodies outside 'sex', examined through the theme, 'The absence of embodied sexuality'. Experiences of positioning the body outside 'sex' in relation to heterosexual relationships will be examined in the themes, 'The absence of 'sex' in heterosexual relationships' and 'The absence of the 'sexual body' without a partner'. It will be argued that discourses of heterosexual 'sex' and relationships have implications for the women's subjectivities as 'feminine' and 'sexual' within intersubjective contexts.

# Positioning The Body Within 'Sex'

## Experiencing bodily ease during 'sex'.

A few of the women reported that their sexuality was either unchanged (Ellen), or had returned to 'normal' following a disruption due to cancer (Sonia and Holly), allowing these women to practice coital sex as they had prior to cancer. Experiences that were reported by these women as informing a 'normative' positioning of their sexual subjectivity included the presence of sexual desire after a period of absence, having a body that was physically capable of performing coital sex, and the absence of relationship distress, allowing the women to practice, and enjoy, sex. The return to 'normalcy' was described by the women saying that their sexuality was, "back to normal"

(Holly), "just the same as normal" (Sonia), that "things have been the same", and "it didn't change my sexuality at all" (Ellen).

The adoption of the subject position 'within sex' centred on the presence of sexual desire and functioning of the vagina as receptive and responsive for coital sex, enabling the women to practice 'normative' heterosex. For example, Ellen said,

I mean it's just as well as you're *inside* is all the same, you know I wanted to see that my, vagina you know that was and all that was-was all going to work and I haven't had any problems lubricating or anything so.

Mm mm, mm mm mm

So, no, it um, all works fabulously. So I guess you could have, if- if nerves had been cut or something like that it would be different.

Similarly, Sonia said,

There wasn't any differences for us um, (inhales) not any dryness, I didn't have any of the other issues that a lot of other people seem to have cause um, it was just back to normal really.

In these accounts, Ellen and Sonia construct their experiences of 'sex' by referencing possible body changes for women with cancer that could potentially disrupt coital sex, such as vaginal dryness or nerve damage that can affect sexual responses. Subsequently, a construction of heterosex as coital sex was adopted in these accounts in which the functioning of the vagina for

intercourse was imperative to the women's accounts of sexual wellbeing following cancer.

The women who adopted a construction of their sexual subjectivity as 'normal' did not report thinking about, or monitoring, their bodies during sex. The sexually functional status of the body allowed the body's functioning to be less visible during sex, enabling an experience of bodily ease and reliability. For example, Sonia said that when resuming her sexual relationship after cancer, her and her partner "just fell into it if that makes sense", saying that it was "like riding a bike yeah we had no- no- no problems whatsoever.

And from then on". Similarly, Ellen stated that the loss of sexual functioning was not something that she had felt worried about, saying,

Um, I was pretty sure that everything worked (soft laugh).

Yeah, yeah yeah yeah

So yeah I mean it was nice to get with him and find that it really did work but ah (soft laugh)...it just wasn't a concern.

In the quote below, Holly contrasts her experiences after her "libido" had returned to "normal", experiencing ease compared to her experiences of sex without sexual desire.

... it was weird I suppose first time after ages and I was like 'oh wow, like that was fine', not as hell as I remember it being a couple of months ago.

Sexual practices and subjectivities were positioned within 'normative' constructions of 'sex' by these women. Further, none of the women reported distress around their current experiences of 'sex'. For example, Sonia and Ellen commented on the enjoyment they experienced through their sexual relationships, with Ellen saying, "It's something that I really enjoy and it's stayed that way". Subsequently, there was an absence of risk to 'sex' in these accounts. Further, such accounts can be read in terms of the corporeality of the cancerous body receding from the women's perception (Williams, 1996), allowing the women to participate in symbolic bodily practices that reinforced a continuity in discursive constructions of sexual subjectivity (Butler, 1993).

# Managing the dysfunctional body during 'sex'.

Many of the women constructed their sexual subjectivity within 'sex' while at the same time managing the absence of sexual desire and body changes from cancer that put at risk the sexual desirability and functioning of their bodies during sex. The women managed their bodies through movement, the restriction of touch, and the arrangement of bodies; shifting the emphasis in sexual pleasure to their male partner; using lubricant as a sexual aid; and discursively normalising decreased levels of sex in their relationships.

Subsequently, these women reported greater consciousness and monitoring of their bodies, which disrupted the "natural flow" of sex, and placed at risk the sexual practices and subjectivity of the women as 'sexual'. For many of these women, the adoption of the subject position 'within sex' was also linked to the context of their intimate relationships, facilitating many of these women to construct their sexual subjectivity as 'relational'. The practices employed by

the women to manage their bodies during sex, and the implications of these practices for the women's experiences of embodied sexual subjectivity, will now be discussed.

Cancer and cancer treatments produced "no go" areas of the body that were no longer desirable to be touched during sex for some of the women, or in Sonia's case, for her partner. For example, Sofia said, "not the scars, but some of the other parts that become off limits, because of what's been done to them". Locations on the body that were positioned as "off limits" to touch during sex included, the cancer site, sites of medical interventions, places of disfigurement, radiation burns, areas of numbness, areas with sensitivity to pain or that were attached to reservations about pain, and body changes that were positioned as sexually undesirable, "gross" or 'repulsive', such as the "shedding" of vaginal tissue due to radiation treatment, and the presence of an ileostomy (Sofia). For example, when talking about her mastectomy scar initially following her surgery, June said,

I don't want him to see this... I'd put my hand over myself all the time.

And if he went to run his hand up anywhere I'd, sort of, stop him.

The avoidance of touch, in this example, can be seen as June exercising agency over her body during sex, managing the discrepancy between possible subject positions of her body as 'sexual' or removed from constructions of 'sex', due to the absence of her breast and presence of a scar that she positioned as "ugly". In another example, Marie responded to my question

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about her partner's touch to her reconstructed breasts by talking about avoiding his touch during sex due to the loss of sensation.

So does he touch your breasts now or is it

Nap. No.

Still a no go

No go.

Yeah yeah

I think maybe later, but I think no point touching them, really. I can't feel anything.

Marie positions touch to her breasts during sex as inconsequential due to her inability to feel sexual sensations from her partner's touch. Her account of avoiding touch suggests that she is managing her own comfort during sex as well as avoiding drawing attention to a sexually problematic part of her body. Further, Marie also discussed avoiding touch to her breasts due to a reservation about pain, saying,

It- it's like when you've got a sore arm you're like (sharp inhale) and you just have that reaction whereas at the end of the day, like if I thought about it logically I would think, 'Well can't hurt it, because I can't feel anything'. But I still have that reservation about it, I think.

Marie's avoidance of touch to her breasts functioned to protect her from the possibility of pain, or anxiety at the possibility of pain, during sex. By

avoiding touch to areas of the body affected by cancer during sex, these women shielded their partners from the sexually undesirable effects of cancer on their bodies and managed their own comfort during sex as well as that of their partners by not drawing attention to aspects of the body that were disruptive to 'sex'. By managing the body in this way, the women can be seen to be engaging in coping strategies to repress aspects of their bodies that may unsettle the act and flow of 'sex'.

In contrast to these accounts, Sonia reported that her partner avoided touch to her chest after the removal of her breasts, saying,

Um, my- my husband though, because he's always been a breast man.

I don't know if it was an epiphany for him, but he's never touched that area of my body since

Yeah

And not that I- it doesn't bother me but it's, his way of dealing with it, you know, cause he's always concerned that he'll hurt me or whatever, you know.

Sonia positions the absence of her partner's touch to her chest as her partner's issue. While referencing her partner's sexual desire towards her breasts prior to cancer, she positions the absence of his touch as conducted out of care and concern, and not significant to her own experience of sex. By positioning the absence of her partner's touch in this way, Sonia is able to avoid her body being positioned as sexually undesirable to her partner. Sonia's account of her partner's lack of touch allows her to minimise the significance in change to

her sexual practices with her partner, avoiding any threat to her sexual subjectivity that this may entail.

In addition to managing touch, the women also reported restricting the movement and arrangement of their and their partner's bodies during sex, to avoid drawing attention to the sexually undesirable effects of cancer, as well as discomfort and pain. In contrast to their accounts of sexual activity prior to cancer, a few of the women reported avoiding particular sexual positions (Gwyn and Sofia), or engaging in fewer sexual positions with their partners (Gwyn and Marie). For example, Gwyn described avoiding discomfort and pain, saying, "There's only one or two different positions that um that intercourse is actually tolerable now, so that's a big change". In another example, Marie reported engaging in fewer sexual positions with her partner as part of slowly renegotiating her sexual relationship after cancer, saying,

... it's not (pause) um (pause) adventurous or, you know, it's- it's just quiet and simple, and you know nice but, not you know sort of, anything what it would have been like, in terms of positions and all that sort of stuff.

In this extract, Marie and her partner can be seen to be renegotiating 'sex' in their relationship by returning to the 'basics' of heterosex, as demonstrated by the positioning of their sexual practices after cancer as "quiet", "simple" and "nice", compared to "adventurous" prior to cancer. It is likely, given the disruption to their sexual relationship during treatment, and the subsequent loss of sexual desire and vaginal dryness reported by Marie, that this process

allowed her and her partner to begin to reestablish sex in their relationship, and come to terms with the changes to Marie's body that had to be managed during sex. Both Gwyn and Marie provide examples of women renegotiating their sexual relationships through coital sex following cancer, with the restricting of movement and posture of bodies signalling a change in sexual practices to be managed due to cancer.

In contrast to accounts of renegotiating sex through coital sex, Sofia reported adjusting her sexual practices to include greater emphasis on non-coital sex as a response to managing parts of the body that were off limits to sex following cancer, such as aspects of her body that she positioned as sexually undesirable. For example, Sofia described her ileostomy as "gross" and acting as a "barrier" during sex, and reported avoiding discomfort by not engaging sexual positions which drew attention to her "poo bag" saying,

... if I was going to have sex I would never be comfortable having sex in the missionary position that was just- awful.

However, further effects of cancer treatment subsequently resulted in additional parts of the body becoming "off limits". For example, Sofia made the following comment when talking about the implications of having a portacath inserted in her chest on her sexual practices, saying,

I guess from a- the point of view of intimate relations it- it- it also has an effect because when you can't, use, you know, your vagina, youyou use other things.

Mm mm mm mm

And then you're boobs are out of action (laughs softly).

With the changes that occurred to the women's bodies, a couple of women reported altering their sexual practices with their partners, including greater emphasis on non-coital sex that was also linked to greater emphasis on their partner's pleasure. For example, Sofia reported a shift in her sexual relationship from a focus on the pleasure of both partners prior to cancer, to her male partner following cancer, saying,

Yeah well the focus is pretty much on him and not so much on me

Yeah yeah

I mean he, I'll do things to make sure he's okay but I don't know whether I'd ever- (voice indicates distress)

Mm

(Pause) I don't know if it will ever be as much fun for me, put it that way

Mm mm

Which is kind of (pause) makes me teary (voice is shaky - emotional)

(pause) because it was one of the things that was really important to

me before

Mm mm

And feeling, feeling confident and feeling that you were, good at sex, that was a good thing um then ah it's like ugh, ew. I guess I can still play that part but I don't get to, be involved the same way you know.

Sofia reports greater emphasis on her partner's sexual pleasure, and constructs a discrepancy in her confidence about sex prior to cancer as opposed to now, where she is not able to "be involved in the same way". Similar to Sofia, Lucy also reported that the focus of pleasure during sex had also changed to be focused on her male partner following cancer, saying,

... for me it was just pleasing him in terms of that's on- that's only what I needed, yeah (spoken with sarcasm).

Mm mm mm

Yeah, but he just thought 'Oh, I have to treat you as normal'. He couldn't get the idea of treating me as, I've changed.

Lucy did not identify the shift to a greater focus on her partner's sexual pleasure within her relationship as part of an emphasis on non-coital sex following cancer. However, it is likely that the sexual practices in her relationship had changed given that she was dealing with severe vaginal dryness with pain on intercourse, an unhealing mastectomy wound, and the development of severe dermatitis to her skin. In the extract above, Lucy also remarks about her need to be treated differently in her sexual relationship, saying that she was not the same as "normal" after cancer. Both Sofia and Lucy attributed the changed emphasis in pleasure in their relationships to the changes to their bodies from cancer. While not unproblematic, attending to

their partner's pleasure allowed the women to continue to take up the subject position 'within sex', and was also likely to be part of managing their sexual relationships when they were unable to take up the same role they had prior to cancer.

A couple of the women spoke about managing their bodies during sex through the use of lubricant as a sexual aid. June and Marie reported experiencing difficulties with vaginal dryness during coital sex that had been significantly disruptive to their sexual desire, sexual experiences and feelings toward sex due to pain on intercourse. As June said, "vaginal dryness is one of the worst of the lot". Further, when talking about the "psychological" impact of vaginal dryness, Marie said,

I really struggle with it, a lot. We- um I- ah- yeah, some of it's like, some of it's psychological. In some ways losing my ovaries I think, was more, impactful than losing a breast. Yeah like I feel like I've- I think because you don't- I don't um, ah, um lubricate as well, stuff like that 'oh god' felt dry with marbles rattling around up in there do you know what I mean, a bit (pause) dried out

Mm mm mm mm

Like a bit old and dried out.

Both June and Marie reported that the use of lubricant was important in managing the effects of vaginal dryness and reestablishing 'sex' in their relationships after cancer. For example, Marie said that the use of lubricant

was part of her and her partner slowly renegotiating their sexual relationship after cancer, saying,

... we're just trying different things and we're using, you know, different lubricants and stuff like that to, you know, make it work.

Further, following the removal of her ovaries, Marie said that in the past she "didn't want [sex], didn't enjoy it", and at the time of interview while using lubricant, she said, "...I never feel like it (yep) Yeah, but when we have sex, I enjoy it". Marie also said,

...even when you use you know an artificial lubricant still you don't relax the same way or tense more... it did hurt for a little while but it doesn't hurt now.

Initially noting an incongruence between her experiences of mind and body, Marie attributed the use of lubricant to a larger process of beginning to relax and become "less detached" from her body, with the hope that she would be able to relax further and become more comfortable with her body sexually in the future. June reported that the use of lubricant was very important, as vaginal dryness could be "very very painful". June and her partner had incorporated the use of lubricant into their sexual practices, saying;

...you have to learn to use various gel aids and that sort of thing; and that becomes a little bit funny in itself, it becomes sexy in itself because you've never had to use those over the years.

For June, the use of lubricant had become something 'novel', rather than purely an additional aid that enabled coital sex to occur. Subsequently, Marie and June's accounts contrast in that Marie positions the management of vaginal dryness as part of a process of renegotiating her sexual relationship, while June positions the use of lubricant as part of the act of 'sex' itself, saying, "Now it's just sort of part and parcel of it". Avoiding pain and dissatisfaction during sex, and creating the conditions to enjoy sex, was important for both women in renegotiating the sexual changes to their bodies following cancer. Further, the renegotiation of sex using sexual aids required the willingness of both partners to continue to renegotiate sex while experiencing discomfort and awkwardness due to the disruption of "flow" during sex.

In addition to changes to sexual practice, a few women managed a decrease in the frequency of sex they had with their partners after cancer. The women contrasted how often they had sex after cancer, with before cancer. For example, Lucy said, "we had, were the kind of couple who would make love two or three times a night... that massively dropped off", and Marie said, "It's not every second, night like we'd like to have it but its (softly laughing) you know, getting to an adequate level". Further, Gwyn said,

So um, and ah he's always been um a very ah lusty fellow he's one of these guys who um, you know prior to that we'd arr- sex would occur at least five or six times a week so, now that we're down to twice um, or three times he's he's okay with that an- and quite happy with that so um, (pause) so yes, he- he's been a paragon shall we say (Laughs).

The women talked about having sex less often while dealing with decreased sexual desire, the management of the bodily effects of cancer on coital sex, discussed above, and increased tiredness and lack of energy. Marie reported experiencing the loss of sexual desire, saying, "I've just got no libido, it's just all too hard, bit tired". In another example, Gwyn reported having coital sex with her partner, in part, as a way of maintaining the structure of her vagina after cancer treatment, saying,

... there's a need to remain physical which has helped a lot because, knowing that you know when you're not feeling well you're inclined you know if you're tired an- and not feeling well you don't generally feel sexy but knowing that, it actually helps um, (pause) um, r- sort of, the elasticity and you know the tissue structure by remaining sexually active has been a huge help actually (laughs)

Yeah

No excuses you know, it's therapy (laughs).

Gwyn reports having coital sex with her partner in the absence of sexual desire, to maintain the structure of her vagina and protect sexual functioning. Despite the loss of sexual desire and body changes that were disruptive to sex, the women managed the decrease in sex within their relationships by normalising the change. As such, the women compared themselves to other couples of a similar age and family situation, meaning that having less sex was 'normal' in the context of a busy life with many demands and pressures on time and energy. For example, Marie said the following:

And then I think to myself, really, how many people my age, with two kids, and a job and a partner, would be having sex more, than we do anyway. I- you know what? I don't think that there's that many couples out there that would be.

Such constructions of the frequency of sex in the women's relationships is suggestive of a positioning of 'sex' closer to idealised constructions of sex in heterosexual relationships, shifting to a 'normalised' position after cancer. Further, by having sex in the absence of desire, the women were able to position their sexual subjectivity within 'sex', maintain their sexual relationships, and ensure the experience of intimacy and sexual connection with their partners. The implications for the relational positioning of the women within 'sex' will be further discussed in the following section.

Positioning the body within 'sex' in the context of heterosexual relationships.

The women's experiences of embodied sexual subjectivity were shaped by their interactions with their partners during sex, as well as broader experiences of relating to their partners. Many of the women who took up the subject position 'within sex' talked about how their partners related to their bodies, and how this shaped their constructions and experiences of their bodies as 'sexual' and 'feminine'. Specifically, the women talked about how their partners helped them feel more comfortable with their bodies by normalising body changes and valuing their 'inner' person, over their 'surface' body changes. Some of the women reported their partner's using more than one

approach, and positioning the women through more than one subject position to construct the women as 'desirable'.

Instances of partner's normalising changes to the women's bodies included, having partners approach the women 'like normal' for sex, indicating that they were not 'turned off' by body changes, and minimising the impact of sexually undesirable or 'repulsive' body changes by 'not noticing', not drawing further attention, or in one case, June's partner positioning her mastectomy site as 'sexual'. As Eva said when talking about the impact of her weight gain to her sexual partner, "Um, it doesn't really make a lot of difference, so I don't think that, he cares particularly". In another example, Sofia spoke about having accidents with her stoma bag, saying,

... cause he's been there through so many horrible, horrible things um, I'm just I'm just so grateful that I haven't woken up in his bed with pooh all around me, it's only been my bed.

Yeah yeah yeah

And when that has happened he's just rolled over, like he's over there not that it's happened on him, but he's just rolled over and gone 'yeah whatever'.

Sofia positions her partner as acting to minimise the attention given to the disruptive and embarrassing experience of spilling her excretion on her bed. Her partner's action of turning over and ignoring the excretion, minimises the effect of the regulatory gaze, discussed in the previous chapter, where breaches of bodily boundaries evoke experiences of failure and self-blame in

the view of others (Chrisler, 2008; Douglas, 1966). As such, her partner avoids viewing her body with a distancing stigmatising gaze, helping to maintain the sexual connection in their relationship. In another example, June reported that her partner actively normalised her body changes by using humour and his own body to draw comparisons in their communication. As June said,

... eventually I sort of well one of the big things was that he's lost a hand when he was a younger teenager, and he just said, one day he just said, 'What's the difference,' he said, 'I've lost a hand,' he said, 'You don't even notice my hand at times,' 'Cause I've, one day I was cutting his nails for him and I said, 'Righto, other hand,' and he just looked at me and laughed; he said, 'You've got so used to it you haven't even noticed.'

### Laughing

And that's the sort of thing that I'm getting at, he doesn't even notice that you're lopsided, he doesn't notice that you've only got one breast anymore.

June described her partner as using his own disfigurement to actively normalise the loss of her breast, and also 'not noticing' the absence of her breast. The actions of partner's that were discussed by Sofia and June functioned to support the management strategies that were employed by the women towards their bodies in relation to 'sex', by lessening the attention given to sexually undesirable effects of cancer. These supportive strategies

allowed aspects of the women's bodies positioned as 'abject' and sexually undesirable to recede from view within partner relationships.

Partner acceptance characterised a couple of the women's accounts of their partner's relating towards their bodies. For example, in contrast to accounts from other women, June said that her partner actively reintegrated her mastectomy scar back into their sexual practice, saying,

No, and as far as the body, look, he'll often run his hand over the scar tissue part, and I used to hate that to start with, I used to feel really withdrawn about that; and he'll say, 'No, that doesn't matter, it's just, you know, it's part of your chest, it doesn't matter.' He often laughs and he just says, 'Oh, you can get closer to me now,' he's pulled me in to him. He said, 'Ah you can get really close.'

June's partner positioned the absence of her breast and scar as 'sexual' by actively including these changes to her body as part of 'sex'. Specifically, including the scar in sexual touch and re-positioning the loss of her breast as an opportunity for greater physical closeness. June reported her partner's acceptance of her body as enabling her to come to terms with the loss of her breast, saying, "he made me to start to feel more comfortable with my body". In another example, Sofia made the following response to a question about whether she had talked to her partner about the way she felt about her stoma:

He says um, yes I have and he said 'I think that it's more of a worry for you than it is for me' (short laugh)

Mm mm

Which was the right thing to say but I don't know if that's what he really thinks.

Sofia talks about her partner not making a 'big deal' of her stoma, something she experiences as "gross". In contrast to June's account, Sofia indicates doubt about the honesty of her partner's response suggesting a degree of vulnerability around her sexual subjectivity due to body changes that were 'abject' and removed from 'normal' and 'sexually desirable' body functioning. The women's accounts of their partner's actions toward their bodies avoided stigmatising the women in their relationships, in contrast to social constructions of the male gaze experienced by the women in broader social interactions, discussed in the previous chapter. By lessening and normalising the attention given to parts of the body positioned as 'sexually undesirable', the bodies of the women, as they were affected by cancer, are allowed to recede from view within their relationships, rather than remaining 'object' or 'abject', and remain sexually desirable to their partners. However, as demonstrated in Sofia's extract above, such a positioning of the women's bodies by partners was not without tensions in the women's accounts due to the remaining internalisation of cultural discourses of femininity and sexual desirability within the male gaze (Ussher, 1997a).

In contrast to strategies of partner support that focussed on the corporeality of the body after cancer, some of the women reported their partners adopting a dualistic construction of embodiment that separated the 'inner' person from the 'outer' body to reassure the women of the continuity of their 'selves' following their cancer. In this construction of embodiment,

the 'inner' person was positioned as being loved and valued over the body, a constant that remained despite bodily change. For example, June said,

A lot of it was perhaps his way of treating me too, because he kept telling me that I hadn't changed at all, and I was still the same person.

And even if I'd have had them both off, it wouldn't have mattered, I was still the same person.

Similarly, when asked about how she thought her partner felt about the changes that had happened to her body, Sonia responded:

We- well I don't think he actually saw it

Mm

Because ah- all he could see, was me.

Mm

And cause the outer shell means nothing.

Similar to instances of resisting discourses of feminine beauty discussed in the previous chapter, Sonia positions her partner as valuing her 'real', 'inner self', over the corporeality of her body, which cannot be controlled due to illness. Such constructions of embodiment position the women's 'selves' as continuous across the cancer trajectory.

Women who were in long-term relationships, where cancer had occurred in the context of an established relational history, made reports of partners who valued the women's 'inner selves'. For example, when talking

about becoming invisible to the male gaze after cancer, Gwyn contrasted her partner through instances of the male gaze that she experienced within broader social interactions, saying the following:

I still look at him and see him at twenty-four and he says he still sees me that way as well. You know he- it's like the different layers are put one on top of each other but he doesn't actually see me as I am now.

Um, which is not a problem for me because I see him as he was then it's sort of one layer on top of each other and um, it's sort of a composite picture of ah, who I am so, I would say less, an- an issue, with him.

It is possible that valuing the 'inner' person over the body could be more problematic in the earlier stages of long-term relationships and 'dating' relationships, where social expectations around the control and presentation of the body are likely to be more confined. For example, when talking about management of her body in a "dating" relationship, Sofia said, "waking up with poo all around you when you're dating is not sexy". Further, the valuing of the 'inner' person over the body may cause tensions or disruptions for some women's subjectivities as 'sexual', as this subject position is in tension with embodied discourses of idealised femininity that place value upon the presentation and appearance of women's bodies as 'sexual' and 'desirable' (Bordo, 2003).

Finally, many of the women who adopted a subject position of their bodies within 'sex', and also reported managing their bodies during sex,

positioned their sexual subjectivity as connected to their current relationship.

As such, the women's positioning of their subjectivities within 'sex' remained vulnerable due to the possibility of the loss of coital sex, or the loss of the women's current relationships. For example, in response to a question about what it would be like if she was unable to have intercourse, Gwyn said,

It certainly would be a lot harder um, living with a very sexually charged man too, there would be a lot of worry on my part that he would be going out um, it would undermine trust I think.

Gwyn positioned her relationship as vulnerable in the case that she and her partner were unable to have coital sex, constructing her partner's sexual desire as biological resulting from "testosterone", and subsequently vulnerable to sexual "temptation" outside the relationship. As further examples of vulnerability, a few of the women constructed their sexual subjectivity as potentially becoming positioned as outside 'sex' if their current relationship ended. For example, Sofia said,

I think I would feel a lot more concerned if I wasn't in a relationship cause I like being in a relationship and I'm not sure I would feel confident about initiating a relationship or dating or, you know, how much

Mm

If I had to, present all this to somebody new.

Mm?

I mean that's still a- as I said before that's still a possibility, I just kinda feel now if something happened I wouldn't even bother (pause) I'd get a cat.

In this example, Sofia adopts a construction of her subjectivity reminiscent of cultural images of older single women as 'spinsters' when considering the possibility of being single (Gordon, 2003). That is, older women without male partners risk being seen as 'asexual' women, without the need of companionship of a male sexual partner. As such, the women constructed their sexual subjectivity as 'relational', meaning that sex would be something difficult to negotiate with a new sexual partner or in the presence of further disruption to sexual functioning. These accounts demonstrate the importance of intimate relational contexts for informing women's sexual subjectivity (Bryant & Schofield, 2007).

# Positioning The Body Outside 'Sex'

# The absence of embodied sexuality.

Half of the sample, eight of the women, reported that they had "no sexuality" or felt "asexual" at the time of the interview due to the impact of cancer on their bodies. The women referred to their loss of sexuality as absolute, and did not indicate an ability to take up alternative subject positions in relation to 'sex'. For example, Philippa said, "Well, I don't feel like a sexual person like this", Joanna said, "Oh, I have no sexuality (laughs) (yeah?) It's all gone", and Christine commented, "I don't feel sexual at all. At all". The adoption of a subject position outside 'sex' was constructed as temporary

or permanent depending on whether the women considered body changes as likely to heal over time, or as having the potential to be negotiated through sexual aids, such as lubricant. As Philippa said, "I know it's doable. It just requires a bit more thinking about or buying something to help or whatever". However, for many of the women, taking up a subject position outside 'sex' was something that was considered unlikely to change over time. As Laura said, in response to my question about how long she had to continue taking her hormonal treatment,

Until I'm well and truly into my own menopause which will be another 10 years down the track. If I make it there. And that would stay during the menopause anyway, so nothing's going to change.

Accounts of the loss of sexuality indicated that the women perceived a changed 'sense of self', or the absence of an experience of 'self' that was no longer available while living with the effects of cancer. Further, these accounts are reminiscent of those described in 'The Abject Body', where experiences of the body are difficult to 'place' within the symbolic order of meaning (Kristeva, 1982), subsequently positioned in relation to what they are not, and constructed outside 'normal' hetero-feminine experiences of the body.

The absence of sexual desire was one of the experiences in the women's accounts that was taken up as a signifier of the loss of 'sexuality', informing the women's positioning of their bodies outside 'sex'. Most of the women who positioned their subjectivity outside 'sex' at the time of the interview reported experiencing long-term loss of sexual desire. In addition, a

few of the women, also reported a period of time during their treatment and recovery where they experienced an absence of sexual desire initially after treatment. Similar to descriptions of the loss of 'sexuality', all of the women who experienced a loss of sexual desire used language to describe the loss as absolute; it was completely absent from their bodies, sense of 'self', and intimate relationships. For example, the following comments were made: "I lost, like, my libido completely" (Holly); "even a twitch or you know a sexual urge or whatever, I don't even get that" (Christine); "I guess at the moment, I see myself as completely asexual. No desire, no, you know, no need, no want" (Laura); and "Nothing, not at all. Not putting out (yeah) under any circumstances. It's like 'could you put out a bit?' Nah. Could not." (Marie).

The functioning of the biological body was constructed as the primary basis for the experience of sexual desire, despite the women also attributing desire to intrapsychic and relationship factors, such as anxiety and emotional distancing. For example, when referring to the experience of sexual desire, the women drew on a construction of the body's functioning as "mechanistic" (Daker-White & Donovan, 2002, p. 89), where corporeal signals of a desire towards sex, such as the "libido", "urges" or sexual "inclinations", dysappeared within the body (Williams, 1998). The loss of bodily sensations of sexual desire contrasted with the women's experiences of embodiment prior to cancer, and was evidence of the dysfunctioning, dysappearing body remaining past acute treatment (Williams, 1996, 1998). The women attributed their loss of sexual desire to the effects of cancer treatments, including, the physiological effects of chemotherapy and hormonal treatments, ongoing

tiredness and lack of energy, significant illness during treatment, and the proximity of menopause at the time of cancer. The construction of sexual desire as a function of the biological body constructs sexual desire as a product of the 'natural' body that was lost to the women due to the *dys* functional effects of cancer treatment on the body. Constructing experiences of sexual desire as a function of the biological body also positioned the body as 'other' to the subjective agency of the women. Similar to other accounts of the loss of sexual desire, such constructions of the embodiment of sexual desire function to distance the women from less desirable feminine subjectivities, such as being a women who does not desire heterosex, being a woman who chooses not to have sex, or who does not fulfil or satisfy the sexual needs of her male partner (Hinchliff et al., 2009).

Many of the women who constructed their subjectivity 'outside sex' unsuccessfully attempted to maintain their sexual relationships through coital sex after cancer. All of these women described experiences of severe pain on intercourse, which meant that penetrative sex became physically impossible. Further, sexual desire was also subsequently disrupted through cyclical experiences of anxiety and fear of pain, leading to avoidance of further sexual experiences. Examples of the women talking about their experiences of pain on intercourse included, "Oh I can't even describe what it was like, it was just sheer agony" (Christine), "just burnt the hell out of me. It was, you know, for weeks afterward it was so painful" (Jackie), and "when I had sex for the first time it nearly killed me" (Lucy). When talking about the impact of pain on feelings towards sex, Joanna said, "I think it's that whole, expecting it to really

really hurt that puts you off even going there. It's a bit too scary (laughs)", and Robyn said, "I was getting a lot of um, discomfort and pain, um on intercourse, and of course that tends to put you off". Further, Laura also spoke about the emotional distress that accompanied painful intercourse, saying,

I mean you know I think it's self-perpetuating as well. You know you get into that whole, 'Oh, this is not going to be a pleasant experience,' and you know, and then you get anxious about it all and then there's guilt associated with it, and frustration.

Yeah

Possibly anger, so there's a whole lot of mental issues going on at that point in time as well.

These accounts are consistent with studies that have examined the relationship between sexual pain and anxiety. Such studies have found that the experience of sexual pain can invoke anxiety and fear of pain at the possibility of future experiences of intercourse, creating a cycle of avoidance of sex (Payne, Binik, Amsel, & Khalife, 2005; Thomtén & Linton, 2013). In the women's accounts, the experience of anxiety became an embodied barrier to engaging in 'sex'. For these women, not being able to perform 'sex' as it is normatively constructed within heterosexuality, contributed to a difficulty taking up a subject position within 'sex' contributing to distress.

A few women talked about unsuccessful attempts to renegotiate sex in their relationships through non-coital sexual practices after experiencing severe pain on intercourse. For example, Robyn and Laura talked about taking

up non-coital sexual practices with their partners, saying that these experiences were not as satisfying. In addition, Christine talked about the possibility of having non-coital sex with her partner, but positioned these sexual practices as being outside her construction of 'sex', saying, "I can do, the manual sex, but I'm not that sort of person". She also did not want to perform oral sex for her partner after having throat cancer. Consistent with other studies that have examined the implications of the coital imperative for heterosexual practices of sex (Gavey et al., 1999; McPhillips et al., 2001), non-coital sex was constructed as 'other' and an alternative to real 'sex' by the women. Non-coital sex was subsequently experienced as less satisfying and desirable by Robyn and Laura, and was accompanied by difficulties performing these practices. For example, Robyn said,

... we'd just look at rather than having actual sort of intercourse we'd do actual sort of other things to get that, from sort of oral sex to whatever to, but it just, it wasn't really the same.

#### And, Laura said,

I mean, he was really good, he was really understanding and said you know, "Don't worry about it, it's fine, we can do other things." Umm, but you know, then there's always that guilt that you're not you know, you know, performing to your full potential sort of thing. Umm (pause) yeah, and frustrating. I mean you know, I can still reach orgasm so it's not like, it's not like there's nothing there, you know.

Both Robyn and Laura positioned their experiences of non-coital sex as not "the same" as coital sex. Further, non-coital sex acted as a reminder for the women of their inability to perform 'sex' as it is taken-for-granted in heterosexual relationships. For example, Laura reported feeling emotionally frustrated, saying, "there's the guilt that it's not right... you might be physically relieved but you're not mentally, you know, you know you still haven't done it properly", and Robyn said, "it wasn't really the same... I certainly didn't enjoy it as much... which tended to sort of make you withdraw a little bit more as well". Laura and Robyn subsequently reported "avoid[ing]" and "withdraw[ing]" further from their sexual partners after attempting to take up non-coital sexual practices. Christine positioned non-coital sexual practices outside her construction of activities that constituted 'sex', saying,

That's why I would be no good as a prostitute (laughs). I can't do the one sided thing. I know, listening to other people, I must be weird, but I'm not the sorta, you know, I believe that it's a two way situation and it's something two people should do together, not one or the other, you know. That's a bit sad.

Christine constructed non-coital sexual practices as less 'mutual' than coital sex, with the act of one partner giving another pleasure as being "one sided". She positioned herself as the 'giving' partner and likens this to sex work as a form of sexual activity involving a transaction between sexual partners, constructing this act as being without a mutually pleasurable exchange. Christine distances herself from the moral implications of cultural discourses associated with women who take up sex work (O'Neill, 1996), saying that sex

should be a "two way situation". All of these women were already experiencing emotional distress, frustration, and guilt due to the loss of coital sex within their relationships and subsequently, further distress accompanied experiences of non-coital sex for Laura and Robyn as a less 'legitimate' way of having heterosexual 'sex'. For example, when talking about attempting to renegotiate 'sex' in her relationship through non-coital sex, Robyn said, "I did get sort of quite upset and- and, distressed by it, because it, you know, it just seemed that whatever I did, didn't seem to work". These accounts demonstrate a failure on behalf of the women to perform a feminine sexual role within their relationships, resulting in experiences of emotional distress in the women's accounts. Further, such accounts shed light on the implications of the coital imperative, meaning that non-coital sexual practices can become problematic when the ability for women to practice coital sex is disrupted due to illness.

# The absence of 'sex' within heterosexual relationships.

The positioning of the women's bodies outside 'sex' had implications for the emotional dynamics of the women's relationships and their subjectivities as sexual partners. Most of the women who were in a relationship at the time of the interview reported positioning their subjectivity as relational and feeling an absence of concern at the loss of sex on their own behalf, as a part of the loss of sexual desire. However, the women positioned themselves as concerned for their partners as they were living with active sexual needs and desires that they were unable to "fulfil". For example, when asked about how she felt about the loss of her sexual desire, Christine said,

Not as much as I thought really... I am not really concerned about it, my concern is towards my partner. What I can't give him, you know?

The women subsequently reported experiencing guilt and inadequacy as partners at the lack of sex in their relationships, adopting a male sex drive discourse to construct their male partners as having an innate biological need for sex (Hollway, 1984). Many of these women also referred to their partner's 'young' age as part of the social construction that young men have a particularly strong biological need for sex. For example, Laura referred to the lack of sex in her relationship, saying, "my husband is young as well". Further, Christine said,

I mean, he is only 57 going on 58 and I am going to be 62. I mean there's a difference there anyway...

The women subsequently spoke about the "difficulty" and "frustration" that their male partners must be experiencing, due to having sexual desire that was unable to be expressed or satisfied within their relationship. By positioning men's desire as an essential biological part of their bodies, rather than, for example, relational or fluctuating, the women experienced fewer possibilities for the positioning of their own subjectivities as sexual partners. For these women, the loss of the ability to engage in coital sex and attend to the sexual 'needs' of their male partners transgressed normal expectations within a heterosexual relationship, which they experienced as guilt. For example, Christine said, "it's not you that you feel guilty about, your partner that you feel guilty about... especially when they're still active". Christine also

reported feeling guilt at her partner's infidelity due to her inability to provide coital sex within their relationship saying, "...that did upset me a little bit and brought the guilt further forward".

The women also reported feeling inadequate, due to being unable to perform their role as a sexual partner following the loss of sex in their relationships. For example, Robyn said,

...certainly I remember being angry, but I think I was just really, upset and it certainly didn't make me feel very good, as- as I suppose a woman, because I c- I couldn't- I ha- I hadn't provided something in our relationship which is is what was sort of expected. Um, so maybe I, maybe feelings of slightly inadequate you know because of that, I don't know.

#### And, Laura said,

Well, I guess being young, you know, like you still feel like you should still be having a fairly active sex life and you know I mean my husband's young as well and you just, I think guilt is the biggest issue on my behalf. That you can't you know, perform your wifely duties and also intimacy.

Both of these accounts are examples of the women positioning themselves as "selling short" their partners. Such accounts demonstrate, in part, a want to desire sex on behalf of the women in order to take up their role as sexual partners in their relationships (Ayling & Ussher, 2008). As such, the women's current embodiment did not allow the women to practice their roles as partner

in socially desirable ways, denying the subject position of a 'good woman' or good partner (Jack, 1991).

All of the women who reported the loss of sex also reported a disruption to affection, intimacy, and subsequent emotional distancing between partners. Most of the women who took up a subject position outside 'sex' and were in a relationship, reported avoiding physical affection out of fear that it could lead to sex, which was something they were not able to provide. For example, Laura said,

... it's not just sex, it's you know, it's holding hands, it's everything.

You don't do anything because, you know, it might lead to something
you don't want so, or can't provide.

Christine positioned her avoidance of physical affection as a protective measure towards her partner, saying,

I don't show much physical affection, for his benefit mainly, because he's still very sexually active.

These accounts suggest that, physical affection was closely associated with sexual practice. The women adopted a subject position where they took responsibility for their partner's desire, being careful not to engage in situations that may sexually arouse their partners, or raise the possibility of sex, to avoid creating difficulty or frustration for their partners, and to avoid drawing attention to their *dys* functional bodies and inability to provide sex in their relationships.

With the loss of sex and physical affection, the women also reported a loss of intimacy in their relationships. For example, Joanna said, "... when you lose that sex, you lose that intimacy, a little bit", and Laura said, "Well, we just don't have an intimate relationship really. [Husband] tries and I pull away, so". In another example, Joanna said,

Um, some days I don't care. I'm just too busy. Um, but other days I, I feel really, really saaad and really, yeah really sad that that intimacy's gone. Because you know when you're not going to have sex you don't lie in bed and chat, you don't cuddle and you don't, because it might led to something I find I do- I veer away from all that (pause) um contact because I don't want it to lead anywhere. And that's really saad, because we were as I said because sex wasn't the biggest thing in our lives but, intimacy was, it was really nice. So I do, I do miss that yeeah.

Further, following the disruption to sex, affection and intimacy, most of these women also reported emotional distancing within their relationships, with Lucy and Robyn reporting that their relationships broke up due to the loss of sex. For example, Joanna spoke about an emotional "wall" coming between her and her partner following her cancer, saying,

... it scared the daylights out of him as well and I don't think he handled it b-, he handled it as well as he could have but I think it knocked him for six. And I think, maybe he (pause) ohhhh not pushed me away but maybe he was just too scared by what was going on so

there was lo- a wall came up between us, so, umm. It took a long time to realise what had happened because it (pause) we were so busy with other stuff that it was- 'hey we haven't had sex for a long time and we're not interested in each other' (laughs). Yeah we still enjoy being with each other, but, more that that, nah.

In this extract, Joanna positions her partner as emotionally confronted by her cancer, removing himself emotionally from the relationship due to fear.

Emotional distancing created greater barriers to renegotiate in the women's relationships if sex, intimacy and emotional engagement were to be reestablished.

The women positioned their partners as supportive when they were "understanding" of the sexual changes that they were experiencing, did not put pressure on the women to have sex, valued the women's survival as more important than sex in their relationship, and stayed in the relationship. For example, Laura talked about her husband demonstrating support by valuing her survival from cancer, saying,

I'm lucky, my husband's quite supportive because I know a lot wouldn't be, and he said, 'Well, you know I don't care, as long as you're here'. So lucky in a way.

Other examples of support included, Holly saying, "it just like, became not a sexual relationship at all, and like, we pushed- but he was so awesome to me and so understanding of that"; Laura said, "he suggests, he doesn't push". In contrast, Joanna commented that despite appreciating the lack of pressure that

she felt from her partner, initiation of sex by her partner may help them reestablish sex and intimacy within their relationship, saying,

And I know that he's very understanding. I- his sex drives not huge anyway which is, lucky. And he'd he'd never, put pressure on. Thwhich maybe he should because maybe then 'oh hey we just neeed to do this'.

Mm

Um, but he's quite happy to sit back and, wait. Which is nice. But um, (inhales) yeeah.

While not overcoming the women's experiences of guilt and inadequacy as partners, accounts of partner support within the women's relationships, avoided exacerbating the women's experiences, or rejecting them. However, none described their partners as actively engaging in issues around the dynamics of emotional distancing that occurred between partners.

# The absence of the 'sexual body' without a partner.

By constructing the body outside 'sex', the subjectivities of women who were without a partner at the time of interview also changed following cancer. These women positioned their bodies outside the norms of heterofemininity and as containing 'risk' due to cancer, reporting that they had "less to offer" a future relationship sexually and had become a "burden" to potential partners through their cancer diagnoses. For example, Lucy said,

I just think people do judge you on your body, and they don't want to take on burdens. So I just feel like I've become two of those two. I've um-, usually I'm the one that offers something to a relationship and I just feel like I've got less to offer.

In relation to the disruption to 'sex' in her previous relationship following cancer, Robyn said,

And I suppose that it also, because of that experience, um (pause) following that the- the surgery it has sort of probably, affected me in (pause) not, perhaps seeking further, you know, ah relationships.

Mm mm

Um (pause) thinking that you know that would sort of put people off or you know they wouldn't want to know and then, you know then, coupled with the sort of breast cancer you think 'Oh, people definitely won't want to know'.

Both of these accounts demonstrate instances in which the women positioned their bodies as less sexually desirable and more risky. Such accounts contrasted to those of the women's experiences of sex and sexual relationships prior to cancer. For example, Lucy referred to her sexual experiences prior to cancer, saying, "it's actually been a fun part of my life". Anna referred to a shift in her subject position around the implications of the possibility of infertility. She said,

I went from being a young, single, vibrant, outgoing person to, well, eventually I would like to be a mother and have family.

These accounts indicate that the women experienced a change to their subjectivities, becoming subject to more constrictive constructions of heterosexual relationships and the male gaze. This appears to have implications for the women's positioning of the possibilities of meeting a potential partner and future roles, such as being a mother, which may become closed off to the women.

In contrast to adopting a construction of the body as less likely to attract a partner, a couple of women took up a more agentic subject position, identifying themselves as having different relationship needs after cancer. Eva and Philippa both positioned this as positive and something they were likely to be more discerning about with potential partners. Possible partners were positioned as being fewer in number and had to be men that "could handle" cancer, with these men also considered more likely to make better partners. For example, Philippa said,

Well you'd only have a relationship with someone who could handle it. So that changes the field of potential partners but those people do exist I know. So, I actually don't know that it's any, would be any harder to find someone like that than to find, I think you're lucks either in or out a bit so and it's also what you want yourself a bit so I think those people exist. In fact, it simplifies things in one way because it's really clear what the terms are. This is the terms of this is what I've

got, this is what I am so you're either into that or you're not, you know.

In this extract, Philippa positions cancer as functioning to clearly define the "terms" of potential relationships, externalising the likelihood of having a partner as due to "luck". These accounts contrasted with those in which the women positioned themselves as subject to dominant discourses of heterosexuality and femininity. Here, although more limited, the women positioned themselves as having needs that can be met by potential partners.

A few women who were not in a relationship at the time of the interview spoke about not seeking, or being interested in a relationship (Anna, Jackie, Robyn, Eva). For a couple of these women, this was positioned as a function of the loss of their sexual desire. As Anna said,

I rarely feel like there's something missing or someone that I'd like to have hanging around.

And Robyn said,

Because I don't have that sort of, sexual drive that you had, so, you're not really worried about seeking you know relationships.

Further to these examples, Philippa and Lucy positioned seeking a relationship as something that may happen in the future but was currently not a concern due to the extent of health issues they were dealing with following cancer treatment. For example, Philippa said,

It seems to just, what it means to me is this is one of the things that's on my plate and um, (pause) it's not something that needs to be dealt with urgently. So it's like an issue that's just sort of there, that's not really pressing.

For Philippa, dealing with a number of short-term health issues related to treatment was of higher priority than longer-term sexual issues. In contrast, Jackie positioned herself as not wanting a relationship reporting that she had more freedom and empowerment outside a relationship, saying that she was "happy" and "why ruin it". As such, the accounts of women who were without a partner and positioned their bodies outside 'sex', demonstrate multiple subject positions and a diversity of experience for women without partners following cancer.

# **Analysis Discussion**

As demonstrated in this analysis, the women in this study positioned their sexual subjectivity within 'sex' and outside of 'sex' after cancer, with some of the women moving within the two positions in their accounts. Those women that positioned their sexual subjectivity within 'sex', practiced coital sex, thus taking up sexual practices within normative heterosexual constructions of 'sex' (McPhillips et al., 2001). As a result, these women were able to position themselves within the 'norms' of femininity and heterosexuality. Women who reported bodily ease and functioning during sex, reported normativity without risk to their embodied subjectivity, while women who managed their bodies during sex reported risk to both their sexual and

relational subjectivities. Constructions of feminine sexuality were strongly related to the couple relationships of the women, with the women taking up practices of 'sex' to do, in part, relational practice, with bodies that were positioned as too risky or unattractive to have sex with a new partner. As such, the sexual subjectivity of these women can be seen, in part, as retaining a 'good woman' subjectivity (Jack, 1991), as women who are able to attend to the sexual needs of their partners and maintain their sexual relationships, a subject position that remained vulnerable to relational loss or further bodily disruptions to 'sex'.

Women that positioned their bodies outside 'sex' did not construct their subjectivities in ways that indicated the possibility for any alternative positioning of their bodies, 'sex', or relational dynamics. For these women, the body remained 'dysfunctional' (Williams, 1996), 'object', 'abject', and out of control. There were implications for the women's constructions of their 'selves' within their relationships with many of the women reporting experiences of guilt and inadequacy as partners, due to their failure to attend to their partner's sexual needs. Further, the loss of intimacy and emotional distancing that subsequently occurred between partners meant that the women's bodies were often positioned as a barrier to the renegotiation of their relational intimacy. For those women who were without a long term partner at the time of the interview, constructions of sexual subjectivity were often more agentic prior to cancer, than after, when women often positioned themselves as subject to social structures which positioned their bodies as less attractive and too risky.

As mentioned previously, the women's positioning of their sexual subjectivity in heterosexual relationships was reminiscent of the 'good woman' 'bad woman' dichotomy described by Jack (1991), where the women drew on dichotomous constructions of subjectivity based on the moral implications of feminine relational subjectivity. For example, being able to perform a 'good woman' role, by ensuring the needs of others are met over the women's, allowed the adoption of desirable and socially valued feminine roles. Women that were not able to meet the sexual needs of their partners had to contend with the moral failings associated with this position, evident in accounts of guilt, inadequacy, and positioning the failure of the body as a barrier to relational engagement with their partners. Further, the risks to sexual subjectivity evident in accounts of practicing of bodily management during heterosex, suggest it was likely that these women were dealing with the likelihood of 'bad partner' positions should they be unable to perform 'sex'. Women who positioned their bodies inside 'sex' did not report instances of relational distress, or reported their partners as taking up relational practices that reinforced their own body management strategies by normalising the women's abject bodies and allowing them to recede from view in the relationship. Women who positioned their bodies as outside 'sex' reported instances of partner support and lack of support, both of which did not actively engage with the disruption to sexuality after cancer, reinforcing the women's own constructions of their bodies as acting as a relational barrier to emotional and sexual engagement with their partners. Overall, these accounts demonstrate that there are relational needs of women who position their bodies

outside 'sex' that are currently being unmet, in part due to 'normative' discourses of heterosexual 'sex' and relationships.

The analysis contained in this chapter can be read in relation to study findings within psycho-oncology where relationship quality has been found to be a mediator of sexual distress for women who are experiencing sexual problems after cancer (Altschuler et al., 2009; Brusilovskiy et al., 2009; Wimberly et al., 2005). Further, partner support of accepting and normalising body changes is important to women's experiences of body change (Altschuler et al., 2009; Moreira et al., 2011). Such findings are also similar to studies outside cancer relating to menopause, where women who experience a decrease in sexual desire or loss of sex experience greater sexual distress in instances where there is a lack of emotional engagement with partners (Dundon & Rellini, 2010; Shiften et al., 2008). As noted by Hyde (2007), these findings need to be examined within the context of the dynamics of heterosexual relationships. As noted in the analysis, discourses of heterosexual sex tend to be structured by 'normative' constructions of sex (Gavey et al., 1999; McPhillips et al., 2001), and taken for granted within heterosexual relationships (Potts, 2002). Further, women's heterosexuality is constructed in relation to men's heterosexuality, with men's heterosexuality tending to be phallocentric (Gurevich et al., 2004), and constructed around acts of subjectivity in which men act out into the world through discourses and bodily practices of which women are subject (Potts, 2002). Further, hegemonic discourses of masculinity construct men as biologically needing sex (Hollway, 1984). As demonstrated in this analysis, the taken-for-granted nature of these

discourses can create difficult ground for women with cancer to negotiate with bodies that are unable to conform to normative constructions of heterosexuality.

# **Chapter Eight: Conclusion**

This chapter will present an overview of the aims and methods used in the study, in conjunction with a summary and discussion of the overall research findings. Implications for theory and practice will be discussed, as will the limitations of the current study, and recommendations for future research.

#### **Summation of Research Aims and Methods**

Studies that have examined women's experiences of sexuality in the context of cancer have identified that disruptions to sexual wellbeing are common following treatment (Ganz et al., 2004; Lange et al., 2009; Traa et al., 2012), and can continue into 'recovery' (Jensen et al., 2004). A review of the literature indicated that women's experiences of sexuality are disrupted through bodily effects of treatment that decrease perceptions of 'body image' and sexual attractiveness (Beckjord & Compas, 2007; Moreira et al., 2011), and damage to the sexual functioning of the body, particularly for the practice of coital sex (e.g. da Silva et al., 2008; Donovan et al., 2007; Ganz et al., 1998). Further, the disruption to sex within heterosexual relationships can damage emotional dynamics and threaten attachment and intimacy (Fobair et al., 2006; Holmberg et al., 2001). In contrast, relationship quality can act as a buffer to psychological distress in the presence of sexual problems (Reese, Keefe, Somers, & Abernethy, 2010; Tang et al., 2010) and diminished body image (Altschuler et al., 2009; Moreira et al., 2011). In addition, many women in heterosexual relationships have also been found to continue having coital

sex after cancer, despite the loss of sexual desire and experience of vaginal dryness (Jensen et al., 2004). In contrast, the sexual experiences of women who are not in heterosexual relationships are currently under-acknowledged. Single women have been found to report higher levels of embarrassment about their bodies, and diminished feelings of sexual attractiveness after cancer, than women in a relationship (Fobair et al., 2006). Studies within psycho-oncology tend to be focus on breast, gynaecological, and to a lesser extent, cancers of the colon and rectum, meaning that sexual problems experienced by women with other types of cancers need to be more fully addressed.

Studies on sexuality within psycho-oncology have tended to focus on the materiality of the body through the adoption of a biological discourse that conceptualises cancer as producing bodily effects that are moderated by 'psychosocial' factors. As a result, a significant proportion of the existing studies that have been conducted examining women's experiences of sexuality after cancer have tended to focus on the material or intrapsychic effects of cancer and cancer treatments (Gilbert et al., 2010b, 2011). At the outset of this thesis I identified that there is a need to address how material and intrapsychic aspects of sexual experience inform, and are informed by, symbolic and discursive aspects of embodiment. While the studies that have examined women's sexuality through a discursive cultural perspective are in the minority, a number of researchers have examined the meanings adopted to make sense of the body and body experiences, including how identities are experienced across the cancer illness trajectory (e.g. Frank, 1995; Mathieson & Stam, 1995; Thomas-MacLean, 2004b). Further, a discursive critique

revealed that existing studies tend conceptualise 'sex' through the heterosexual construction of the coital imperative, reinforce cultural constructions of femininity in relation to the dynamics of heterosexual relationships, and position psychological distress as a function of gendered risk and individual pathology. Without examining women's subjectivity within a socio-cultural context, research risks positioning experiences produced by gendered cultural structures as a product of women's bodies and a function of individual pathology (Lafrance, 2009). In the light of this critique of previous research, the current study aimed to provide an account of women's experiences of sexuality in the context of cancer employing a fuller account of what the body is, and how we experience the body as gendered.

At the outset I acknowledged that the materiality of changes to women's bodies after cancer was important to consider, as part of the corporeality that women negotiate in their sexual experiences. This is particularly important, as studies have suggested that these body changes and ongoing risk of cancer recurrence can continue to be problematic after the conclusion of treatment (e.g. Little et al., 2002; Thomas-MacLean, 2005), and can provide fragile conditions through which people make meaning of their subjectivities (e.g. Kaiser, 2008; Mathieson & Stam, 1995). Further, I argued that cultural discourses of femininity, sexuality and heterosexual relationships produce particular limitations and possibilities for women's experiences of their sexual embodiment (Ussher, 1997b). Such an account conceptualises femininity and heterosexuality as performed through bodily practice (Butler,

1993). As such, I adopted a critical realist epistemology with a material-discursive-intrapsychic framework for the current study.

The aim of the research presented in this thesis study was to examine women's experiences of sexual embodiment in the context of cancer. The research questions used to address this aim were: How do woman make sense of their body experiences and sexual 'selves' in the context of cancer? How do women understand and experience their sexual relationships in the context of cancer? In order to address broader gender discourses that contribute to the production of women's experiences of sexuality after cancer and extend the current findings of studies that tend to focus on breast, gynaecological and, to a lesser extent colorectal cancers, a sample was selected across age groups and different cancer types. Sixteen women were interviewed who were aged between 20 and 71 years of age, and were diagnosed with a range of different types of cancers.

# **Discussion of Findings**

The overall finding of this study was that the corporeality of the cancerous body disrupts hegemonic discourses of femininity and sexuality, with implications for the way that women experience their embodied sexual subjectivity. The women's accounts of embodiment were characterised by descriptions of bodies that were unable to be contained, unable to be controlled, excessive, and transgressive of bodily boundaries and hegemonic discourses that structure women's experiences of sexual embodiment. As such, the women I interviewed positioned their bodies as problematic, through

constructions of embodied experiences that breached binary discourses of the body, including subject/object, mind/body, and public/private. Subsequently, the relationship between the women's bodies and 'selves' became unsettled, challenging the adoption of 'legitimate' feminine and heterosexual subject positions for the women. Women's bodies already occupy culturally liminal positions (Ussher, 2006), as part of cultural contexts that value women for their bodily appearances (Bordo, 2003; Fredrickson & Roberts, 1997), and sexual their desirability to men (Ussher, 1997a). In the present study, cancer appeared to heighten the women's experiences of marginalisation, in the context of existential threat, the uncertainty of illness, and sudden bodily trauma and change. The women's constructions of their bodily changes functioned to bring into visibility the social structures that regulate women's experiences of their bodies, leaving many of the women outside desired, valued and legitimate forms of 'doing' feminine sexual subjectivity (Butler, 1993), with many of the women positioning themselves as having 'lost' their sexuality all together.

Consistent with a poststructuralist approach to subjectivity (Gavey, 1989; Henriques et al., 1984), the women adopted multiple subject positions to negotiate their experiences of embodied sexuality across different social and relational contexts. Experiences of the women's cancerous bodies as problematic were reinforced through the different contexts that the women experienced in their everyday lives, identified in each of the three cultural contexts of analysis: the medical system, abject bodies, and 'sex'. For example, interactions with the medical system transitioned the women from an

initial state of experiencing their bodies as 'subject', to highlighting the body's functioning as 'object' (Williams, 1996), distancing the women from embodied discourses of feminine sexuality in favour of discourses of survival. At the conclusion of acute treatment, the women were often dealing with a range of different physical effects of cancer and cancer treatments that often made the *re*-embodiment of 'sex' problematic (Gilbert, Ussher, & Perz, 2013). Such experiences problematised notions of 'recovery' and were characterised in terms of a difficulty making sense of past and present 'selves', through the disruption of embodied discourses of feminine sexuality.

The liminal position of the women's bodies was further demonstrated through the women's accounts of the 'abject' body, which also revealed the body as difficult to make meaning of, as well as confronting, repulsive, out of control, and removed from embodied discourses of idealised femininity. Subsequently, many of the women described bodies that were positioned as less sexually desirable and less socially valuable. The male gaze, and broader social regulatory gaze, were found to play a significant role in reflecting back to the women the positioning of their sexual subjectivity. Indeed, many of the women reported experiences of becoming invisible to the male gaze, and more visible to instances of regulatory social gazes that distanced their bodies from social 'norms', stigmatising their bodies in this process.

Finally, in the cultural context of 'sex' and heterosexual relationships, normative discourses of heterosexuality and idealised femininity structured the women's accounts of their bodies as being within or outside 'sex'. The women's descriptions of their bodies were most often characterised as

problematic to 'sex', in need of management during sex, or in terms of an absence of sexuality. As such, 'sex', and being a 'sexual' woman, can be seen, not as a categorical or essential quality of the feminine body, but a social construction produced across complex, fragmented, and non-unitary constructions of bodily experience (Malson, 1998). Such a finding has important implications within a cultural context that constructs 'sex' and hetero-femininity as taken-for-granted (Potts, 2002).

Following the disruption to hegemonic discourses of femininity and sexuality, the women engaged in material and symbolic practices of body management. This can be read in part as the women regulating their bodies as part of the function of the social, moral, emotional and relational consequences of bodies that breach boundaries of hegemonic discourses (Waskul & van der Riet, 2002). They can also be read in terms of coping strategies employed by the women to exercise agency over their embodied subjectivities through the preservation of survival, avoiding further marginalisation, and disruption to sexual relationships, or the possibility of sexual relationships.

The women's accounts of agency constructed a problematic relationship between the 'self' and body through subjectivities that were performed through body practices focused on *how* the body was seen, or not seen, and discursively, what aspect of the body was positioned as the 'self', and what aspect of the body was symbolically 'split' and removed from the 'self'. Such accounts can be read as examples of psychic splitting from a Lacanian perspective, where repressed symbolic meanings attached to the

corporeality of the body continually fragmented and disrupted the women's constructions of subjectivity, making unified representations of 'self' problematic (Lacan, 1966). Body practices subsequently allowed the corporeality of the body with cancer to recede from view of cultural 'Others' - both from the social regulatory gaze and women's intimate relationships - preserving a positioning of the body as 'sexual'.

Further, a few of the women externalised the marginalisation that they experienced due to the social positioning of the corporeality of their bodies by resisting discourses of feminine beauty and confronting the male gaze. As a function of the role of hegemonic discourses in the Australian cultural context, and the materiality of the body, the women were unable to entirely separate themselves from the cancerous body, meaning that many of the women were continually managing their bodies, or engaging in ongoing work to resist hegemonic discourses. Bodily practices that were employed in the production of the women's subjectivities became heightened due to the corporeality of the cancerous body. Subsequently, many of the women had to engage in ongoing 'work' to repress and conceal their bodies, allowing them to adopt more legitimate discourses of their embodied subjectivities. Overall, accounts of the women exercising agency over their bodies demonstrate that women's bodies act as contested sites of cultural discourse (Malson, 1998). Further, cancer appears to function as an experience that heightens these cultural dynamics for many of the women.

Marginalisation and stigma was expressed by the women through the gaze of a cultural 'Other' (Foucault, 1975). Across the three analysis chapters,

the women I interviewed made sense and experienced their bodies through cultural gazes, that often functioned to distance the women from a dominant cultural 'Other', through which they constructed their subjectivity. As such, the women experienced a difficulty making meaning and symbolically 'placing' their bodies within the symbolic order according to the cultural 'Other', through biomedical discourses of the body (Foucault, 1963), the male and regulatory social gaze (Fredrickson & Roberts, 1997; Ussher, 1997a, 2006), and the structure of the 'heterosexual matrix' (Butler, 1990). In other words, the gaze of the cultural 'Other' in each of these contexts functioned to position the women's bodies through discourses that constructed the women's bodies outside desirable hegemonic cultural positions of feminine sexuality. It is important to note that the gaze of heterosexual masculinity permeated many of these social interactions and was often internalised by the women (Ussher, 1997a). Subsequently, the women had to negotiate dominant discourses that positioned their bodies, and subsequently their subjectivities, as 'feminine' and 'sexual' (or not). Such experiences contained risk and threat to the women's subjectivities, through which they had to negotiate liminal cultural ground, producing descriptions of experience characteristic of stigmatisation and marginalisation and often separating the women from desirable forms of femininity that are sanctioned as legitimate and sexually desirable to men.

It is important to note that some of the women experienced a 'gaze' in their relationship that contrasted with the marginalising effects of dominant cultural gazes. These women's partners affirmed their bodies by normalising and positioning them as sexually desirable, reinforcing many of the strategies used by the women to take up a subject position 'within sex' and allowing disruptive and sexually problematic bodies to recede from the sexual dynamics and practices within the relationship, maintaining the sexual connection between partners. In contrast, the distancing of emotional dynamics by those women who positioned themselves outside of 'sex' is reminiscent of the affects of cultural gazes that marginalise and separate the women's bodies from 'normal' hetero-femininity, likely reinforcing these marginalising experiences for the women. These differences demonstrate differences between stigmatising and sexual gazes, with stigma separating and creating distance between the women and cultural 'Others', and sexual gazes drawing the woman towards cultural 'Others'. These findings suggest that the intersubjective context of heterosexual couple relationships can potentially counteract the effects of stigmatising cultural dynamics, although as seen in the analysis, this was experienced in the context of normative heterosexual relationships and not without risk to the women's subjectivities as 'sexual'. Women who reported support from their partners that counteracted the effects of stigma also remained engaged in practices of coital sex, while managing bodily discomfort or pain.

This analysis of the women's experiences of problematic bodies and the disruption of hegemonic discourses points to the likelihood of difficulty for the women when attempting to access meanings that position the women's bodies as legitimate. Idealised femininity and the social norms of heterosexuality were used as comparison points for the women's experiences of embodied sexuality throughout the women's accounts. For whilst previous

research has reported that some couples renegotiate their relationships with a flexible approach to 'sex' and outside the coital imperative, suggesting that couples are able to resist hegemonic discourses of 'sex' (Ussher et al., 2013), none of the women in this study reported successfully renegotiating sex outside the coital imperative. Further, accounts of sexuality prior to cancer were often constructed in terms of the women exercising their sexual agency, compared to accounts of sexuality following cancer, when women positioned themselves as subject to, and failing, idealised discourses of femininity and normative discourses of heterosexuality.

These findings demonstrate the dominant role that hegemonic discourses play in structuring women's experiences of their bodies, 'sex' and 'selves'. However, the findings also suggests that following cancer many of the women were negotiating issues of legitimacy around their experiences of sexual embodiment due to difficulty in being able to adopt discourses of feminine sexuality closer to those of idealised femininity (Bordo, 2003; Ussher, 1997a). Further, discourses of feminine sexuality are deeply connected to moral implications for women (Jack, 1991), which were evident in the present study in the women's accounts of feelings of risk, loss of control, failure, self-blame, shame, guilt and inadequacy related to their embodied sexual subjectivity. Such findings are suggestive of the lack of legitimacy that many women experience around their sexual subjectivity after cancer.

The analysis of women's experiences of embodied sexuality contained in this study made reference to words indicative of the occupation of discursive 'space' by women's bodies with cancer. For example, the analysis

referred to 'limits', 'margins', 'inside', 'outside', the body as a 'barrier' to normalcy, and 'sites' of meaning. Such positioning of women's bodies and sexualities in the context of cancer are indicative of the difficulties that women can face making sense of their experiences. Conceptualising issues of legitimising the positioning of women's sexual embodiment in the context of cancer in this way lends itself to the question of how to create legitimising cultural 'spaces' for women's bodies? There are conditions to the experience of cancer that are more commonly considered by research, including particular body changes, experiences of uncertainty and existential risk. The question of how to create legitimate spaces for women's bodies is also related to broader cultural dynamics around women's bodies and how to legitimise experiences in the context of dominant cultural discourses of femininity and sexuality. As such, the discussion of implications of this study will draw on feminist approaches to legitimising women's experiences.

# **Implications for Theory and Research**

The findings of this study demonstrate the limitations of biomedical and psychological approaches, showing the importance of addressing discursive structures and dynamics as part of embodied sexual subjectivity. The findings of this study suggest that we need to create space to recognise both the corporeality of women's bodies and legitimise women's subjective embodied experiences of sexuality. Dominant discourses of femininity and heterosexuality are implicitly reflected in the focus of existing studies on women's sexuality after cancer. For example, research tends to focus on women with cancers culturally assumed to concern women's sexuality, such

as breast or gynaecological cancer, and to a lesser extent colorectal cancers. The sexual changes experienced by women with these types of cancers are important, however, the findings of the present study suggest that sexual changes are experienced by women across a range of cancer types. Further, the findings in this study suggest that it is important to include both women who are not in long-term heterosexual relationships, as well as women who do not have regular sexual partners. Finally, contrary to many of the assumptions in the existing literature that sex is primarily a concern of younger women, sexual concerns were experienced by the women in this study across age groups, including younger and older women (Hordern, 2008). Further, these findings suggest that is it important for studies to move beyond constructing sex as coital sex, to include other forms of sexual practice, as well widening the focus of 'sexuality' to included non-heterosexual subjectivities, in order to account for the extent of women's experiences. As such it would be important for these women to be included in future research.

## **Implications for Policy and Health Services**

Women's experiences of sexuality and embodiment are deeply connected to moral implications for women, many of which are about internalising moral failures as an implication of being unable to take up 'good woman' feminine subjectivities (Jack, 1991). Therefore, it is important for health policy to reflect issues of gender and sexuality based on connections between 'big picture' cultural dynamics and the gendered experiences of individual women, including the internalisation of cultural dynamics prevalent in experiences of shame, guilt, self-blame and failure (Lafrance, 2009;

O'Grady, 2005; Ussher, 2011), through being aware of complex gendered dynamics that women are negotiating. Part of acknowledging the connections between cultural dynamics and individual experiences would involve recognising the different barriers that can be experienced by women who are negotiating experiences of femininity and sexuality following cancer, including cultural and political barriers to the negotiating sexual changes.

Gendered cultural barriers to the renegotiation of women's sexuality are often not acknowledged in existing psycho-oncological studies (Hyde, 2007), and as such, it may also be the case that cultural barriers relating to gender are not fully acknowledged in the practice of health services and health professionals that have working relationships with women who are negotiating cancer experiences. As such, health policy needs to recognise the lived complexity of experiences of gender and sexuality, and give 'space' to women's experiences beyond dominant discourses of heterosexuality and femininity.

Part of acknowledging the connections between 'big picture' cultural dynamics and individual gendered experiences in policy involves critical reflection on what is brought to mainstream health services. This includes what is taken-for-granted as 'feminine' and 'sexual' in health practice and how health professionals bring these cultural dynamics into interactions with women who have cancer. Important questions to consider include; how do women who use health services experience their sexuality?; what are the implications of this for legitimising experiences that do not confirm to hegemonic discourse? and what are the implications of the compulsory nature of coital sex and relational dynamics of heterosexual relationships for

women's subjective experiences of sexuality?. These questions may challenge the assumptions around heterosexual women's experiences in mainstream health services.

As part of formulating the implications for health services and health professionals in this study it is important to acknowledge that dominant discourses of gender and sexuality are deeply inscribed within our understandings of 'self' and subjectivity in the world (Foucault, 1985). Further, consistent with the aim of creating space for women's bodies, acknowledging the diversity of women's embodied experience is important, accepting that in terms of clinical practice, it is unlikely that 'one size will fit all' (O'Grady, 2005). However, driven by guiding principles formulated through the cultural dynamics and experiences described by the women in this study, there are a number of implications for health service practice that can be identified.

Firstly, it is important to consider the power of language in negotiating and legitimising experiences of suffering when communicating with women around sexual changes after cancer. Many of the women interviewed in this study demonstrated difficulties in making meaning of their bodily and sexual changes, due to the lack of availability of language to legitimately name their experiences, and the marginalisation of experience through dominant discourses within language. Therefore it is important for health services and those working with women around sexual changes after cancer to be aware of the influence of cultural dynamics on women's experiences of suffering following sexual changes, and the role that hegemonic discourses of

femininity and sexuality can play in marginalising women's sexual experiences, particularly when women are unable to attain particular cultural standards of femininity.

Feminist approaches to narrative therapy tend to address the internalisation of cultural dynamics by women, by focusing on externalising these dynamics (O'Grady, 2005). Such approaches include narrative approaches that are focused on 'externalising' women's experiences, highlighting life events that emphasise moments of difference and transformation as a way of 'restorying' women's experiences (O'Grady, 2005). Narrative approaches are not without criticism, as they take place within the cultural contexts that they are functioning to critique risking the reinforcement of cultural discourses (O'Grady, 2005). However, these approaches may help change the narratives that are used to construct 'self' and embodied experiences for women with cancer. While not expected to be unproblematic in the context of dominant cultural dynamics, narrative approaches may provide potential ways of opening up discursive space around the corporeality of women's bodies and their embodied experiences of sex.

Some of the principles of narrative approaches and negotiating different ethics of self-care toward the 'self' (O'Grady, 2005), could be harnessed in embodied practices that allow the body to be re-positioned and experienced beyond hegemonic discourses of femininity and sexuality within therapeutic health services. For example, some of the women in this study spoke about repositioning their bodies as sites of personal transformation. Further, art and creative practices have been used, particularly with

experiences of breast cancer, as ways of 'restorying' the body in public spaces, and potentially challenging hegemonic discourse (Bell, 2006; Spence, 1995). Further, such approaches may have potential in individual and small group therapeutic health practices to allow women to make sense of subjective embodied experiences in ways that provide an avenue around the limits of spoken language. As such, creative practices may help produced different discursive meanings around the body in ways that negotiates barriers to legitimately naming experiences as well as providing an avenue for exploring issues of ownership over the body and bodily experiences.

A number of studies in the area of cancer and sexuality have advocated a relational approach to experiences of sexual problems after cancer that may be helpful for health services to employ. As noted previously, there are a number of studies that have suggested that relationship quality is a buffer to psychological distress (Holmberg et al., 2001), sexual distress (Tang et al., 2010), and lowered experiences of 'body image' following cancer (Moreira et al., 2011). Further, studies suggest that the coping strategies of both partners are interrelated (Badr et al., 2010; Giese-Davis et al., 2000), suggesting this may have implications for how sexual issues are negotiated in relationships. In addition, relational approaches have been advocated from a feminist perspective as a way of shifting the emphasis in self-blame from the women to the relationship (Kayser, 2005). It is important for relational approaches to acknowledge the cultural dynamics of heterosexual relationships (Hyde, 2007), so as to not reinforce these structures, but to create further space within relationships for women's experiences. This is particularly important in the

light of the findings of the present study, which suggest that women are often living with 'risk' to their relationships on account of sexual changes, and are also living with unmet relational needs due to emotional distancing and lack of connection with their partners due to the positioning of their bodies as barriers to engagement.

Health service approaches to women's experiences of sexual embodiment after cancer that conceptualise sexual problems as a relational issue may benefit from 'flexible' approaches to definitions of 'sex' (Reese et al., 2010). Such an approach may help shift the taken-for-granted status of coital sex within heterosexual relationships, as well as legitimising the role of non-coital sexual practice. 'Outer' practices of sex have been suggested as a way of negotiating alternatives to the cultural discourses implicit within heterosexuality (Potts, 2002). Further, legitimising non-coital sexual practices may help negotiate the positioning of women's bodies with cancer as barriers to sexual intimacy. As such, sexual practices that involve engaging with the potential for the giving and receiving of sexual pleasure between partners may include, massage, mutual stimulation, partner masturbation, oral sex, hugging and kissing, etc. (Gilbert, Ussher, & Perz, 2013; Ussher et al., 2013). As was reported in the present study, there are important issues to take into account when advocating such approaches to sex, including emphasising the place of women's sexual pleasure within the relationship (rather than an implicit emphasis on men's sexual pleasure), and positioning non-coital practices as 'actual', legitimate options for 'sex'. It is important to note that there may be other difficulties to negotiating these practices for women who are forming

new sexual relationships without an established relationship history. In this case, it is also important to consider how single women communicate with potential sexual partners in dating situations in order to have their sexual needs and desires met.

For those women who are in long-term relationships, therapeutic health services could focus on forms of relational intimacy, other than sexual intimacy, as pathways to renegotiation of relational intimacy, particularly in instances where emotional distancing has occurred due to the loss of sex forming a barrier to the relational renegotiation. Emphasis on other forms of intimacy, including shared aspects of experience that bring about a sense of enjoyment and closeness between couples may help 'bridge' emotional dynamics that are too confronting to directly address through sex, when coital sex is not possible. Further, the diversification of relational practices and shifting of the emphasis on 'sex', may possibly help shift the emphasis of blame from the women's bodies and begin to create space for communication that enables women to have their emotional and sexual needs met in their relationships.

Finally, when talking about sex and sexuality within health services, it is important to consider that there are many life events than can disrupt experiences of 'sex' and sexuality for both men and women, including and not exclusive to, other forms of acute and chronic illness, injury, disability, stress, trauma, mental illness, ageing, and reproductive events such as pregnancy and menopause. Some of the experiences described in the women's accounts within the present study are specific to cancer, and some of the instances of

life experiences described here contain their own forms of stigma. However, considering experiences of sex within a broader lifespan picture may help normalise disruptions to sex that can occur because of cancer, creating space for women's embodied experience after cancer.

## **Limitations and Implications for Future Research**

There were a number of limitations to this study that will be discussed in the context of recommendations for future research. Firstly, this study was focused on the experiences of heterosexual women. As such, the women drew on dominant discourses of femininity and sexuality as they relate to heterofemininity. Further, the women's experience of making sense of sexual embodiment was performed under the gaze of the heterosexual male 'Other'. The implications of this focus are that experiences of bisexual, lesbian and transgender women were not addressed in this study. Future research could address this limitation by examining the way that bisexual, lesbian and transgender women construct and experience their sexual embodiment, including their experiences of sexual embodiment in same-sex relationships. Existing research suggests that lesbian woman are more likely to privilege bodily function over bodily appearance, and are less likely to experience sexual concerns, or disruption to sexual activity after cancer (Arena et al., 2006). Further, women partners of women with breast cancer have been found to be important sources of emotional and practical support (White & Boehmer, 2012). Such findings suggest that there are important implications for understanding how lesbian women experience their bodies, sexualities and relationships in the context of cancer. Further, by focusing on women's

experiences outside heterosexual couple relationships, such studies could shed further light on the functioning of normative discourses of heterosexuality, which structure heterosexual women's experiences of their bodies.

The current study did not interview male partners, meaning that this study was not able to ascertain how men were making sense of the partner's embodied sexual changes, how the men were dealing with sexual changes in the relationship, and how men were negotiating their own constructions and experiences of heterosexual masculinity with partners affected by cancer. Further, it is unknown what coping strategies the men may have been used to relate to their partners, their attempts and constructions of support, as well as emotional experiences in negotiating relational dynamics. Future research could include both men and woman partners as a relational dyad in order to examine the constructions and experiences across and between partners within a heterosexual relationship. Current research suggests that partners employ similar coping strategies (Badr et al., 2010), and that discrepancies in experiences around sexuality do exist (de Groot et al., 2005; Stafford & Judd, 2010). As such, studies that include both partners within a heterosexual relationship could highlight the discrepancies and similarities between partners, as well as how each partner negotiates particular aspects of heterofemininity and hetero-masculinity around sexual changes after cancer. The findings of such studies may shed further light on the functioning of heterosexual relational dynamics around women's experiences of sexuality, as well as highlighting areas of creating space for women's experiences in heterosexual relationships, enabling greater relationship support.

Many of the findings in this study were made in the context of broader understandings of women's experiences of sexuality and heterosexuality. It is possible that these findings may relate to women's experiences of other forms of chronic illness (Basson, 2010). Future research could examine women's experiences of sexual embodiment and couple relationships in the context of chronic illnesses other than cancer. This would have important implications for confirming the women's experiences that were described in this study, as well as examining the way other culturally liminal health conditions affect women's experiences of sexual embodiment. Such studies may hold particular resonance for women, as they tend to be diagnosed with more marginalised chronic illnesses, that is, chronic illnesses that are more difficult to diagnose, identify specific biological causes, and have symptoms that are exacerbated by stress (Lafrance, 2009). Further, women occupy marginalised 'psychosomatic' margins of illness more frequently than men (Moss & Teghtsoonian, 2008). Examining the women's subjective experiences of sexual changes from a gendered perspective may provide further light on women's experiences of sexual embodiment, as well as chronic illness. Particularly, as these conditions are often more marginalised both within medicine and broader social and cultural discourses, meaning that a reduction in social awareness may have implications for coping strategies around sexual experiences in heterosexual relationships. Such studies would allow conclusions about how women experience sexual embodiment across chronic illness contexts.

Finally, as noted previously, nearly all of the women who participated in this study were Anglo Australian. In addition, the study also drew on

Western feminist theory for understanding women's experiences of sexual embodiment. As such, it is likely that the findings in this study will resonate with women's experiences in similar Western cultural contexts (Gavey et al., 1999). However, it is important to note that cultural differences relating to ethnicity may inform women's experiences of sexual embodiment in ways that were not captured by this study (e.g. Rubin, Chavez, Alderman, & Pusic, 2013). Given the culturally intimate 'nature' of bodies and bodily experiences, it is important to note that women from ethnic cultural backgrounds, outside of Anglo Australian women and including Indigenous women, experience their sexual embodiment in ways that both intersect and differ from those of the women in this study (Davis, 2008). The cultural representations of idealised femininity are largely based on characteristics represented by white feminine bodies, with dominant constructions of feminine 'beauty' based on the facial features, skin, and hair of white women (Bordo, 2003). As such women from non-white ethnic groups may experience additional forms of marginalisation, or different experiences of embodied changes, following cancer.

Further, as demonstrated in this study, experiences of the embodiment of illness are experienced in the context of interactions with the medical system. Women who are from cultural and language groups other than Anglo Australian may also experience other forms of marginalisation within the medical system through cultural discrepancies in knowledge and experiences of the body, which could inform the women's experiences of sexual changes following cancer (Treloar et al., 2013; Ussher et al., 2013). Further, some ethnic cultural groups, including Indigenous cultures, may have different ways

of 'knowing' and 'telling' embodied experiences outside those informed by Western feminist theory in this study (Simmonds, 2011). As such, cultural groups outside those represented in this study may have other forms of 'doing' cultural knowledge about gender and sexuality that create other avenues for negotiating sexual differences and changes within heterosexual relationships (Aspin & Hutchings, 2007). One of the strengths of the present study was the privileging of women's subjective experiences, and examining sexual embodiment through discursive structures and dynamics.

## **Concluding Remarks**

This thesis examined women's experiences of sexual embodiment as it occurs within the context of cancer. To extend current studies, women from a range of different cancer types, ages, and relationship contexts were interviewed. The thesis demonstrated that hegemonic discourses of femininity and sexuality become disrupted by the corporeality of the cancerous body. This made it difficult for women to make meaning of their experiences of sexual embodiment across the cancer chronic illness trajectory. Further, the positioning of the body as 'abject' was related to experiences of self-blame and shame, while positioning of subjectivities that resisted the abject body resisted hegemonic discourse and re-positioned the body as a site of personal transformation. Finally, the women's positioning of their bodies in relation to social constructions of 'sex', structured by hetero-normativity, meant that many of the women positioned their bodies inside or outside 'sex', with implications for their feminine and relational subjectivities. These findings suggest that the culturally liminal space that women's bodies occupy becomes

heightened with experiences of cancer, and that strategies aimed at creating discursive 'space' around women's bodies and legitimising their experiences of sexual embodiment are needed within research, policy and health services.

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# **Appendix 1: Invitation to Participate in Research**

School of Psychology College of Arts Locked Bag 1797 Penrith South DC NSW 1797 Australia



#### INVITATION

# Study Title: Women's Experiences of Sexual Embodiment in the Context of Cancer

Thank you for completing a questionnaire as part of the Australian Research Council study exploring 'Multiple perspectives on sexuality and intimacy post-cancer, leading to the development and evaluation of supportive interventions'. This project is providing valuable knowledge into experiences of sexuality and intimacy for people with cancer and their partners. Your contribution to this study has been greatly appreciated.

You have indicated an interest in participating in an individual interview as part of the Cancer and Sexuality project. I would like to invite you to participate in research that is being conducted as part of a PhD scholarship within the project. This research is being undertaken by Chloe Parton, a PhD Candidate within Gender Culture and Health Unit: Psyhealth, School of Psychology, University of Western Sydney. The Supervisory panel for this research are: Associate Professor Janette Perz (primary supervisor), Dr Emilee Gilbert and Professor Ian Wilson.

The PhD research is specifically focussed on an in-depth exploration of women's experiences around the changes to their bodies as a result of cancer and the impact of these changes on how they experience sexuality. The study will be looking across a broad range of experiences with cancer. This research will contribute further indepth knowledge into women's experiences of their bodies, sexuality and intimacy in the context of cancer.

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the information sheet carefully and discuss it with others if you wish.

## Contact details

When you have read this information, if you would like to take part in the interviews, please contact Chloe. If we don't hear from you, Chloe will follow up this letter after two weeks with a phone call to see if you are still interested in participating in an interview. Also, if you have any queries, or would like to know more at any stage, please do not hesitate to contact Chloe or her supervisor Associate Professor Janette Perz.

Chloe Parton
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Gender, Culture & Health: PsyHealth
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Thank you for taking the time to consider this invitation.

# **Appendix 2: Participant Information Sheet**

School of Psychology College of Arts Locked Bag 1797 Penrith South DC NSW 1797 Australia



#### **PARTICIPANT INFORMATION SHEET**

# Study Title: Women's Experiences of Sexual Embodiment in the Context of Cancer

This research is part of a PhD scholarship within an Australian Research Council (ARC) funded project which is exploring experiences of sexuality and intimacy following cancer. The ARC study is being conducted at the Gender, Culture and Health Unit: PsyHealth, School of Psychology, University of Western Sydney funded by the Australian Research Council, in partnership with The Cancer Council of New South Wales, National Breast Cancer Foundation, Westmead Hospital, and Sydney West Cancer Network Psychooncology Service, in conjunction with the Centre for Values and Ethics in Law and Medicine, University of Sydney.

The PhD research will take a specific look at how women experience changes to their bodies and sexuality following cancer.

Participation in this PhD research will not effect your involvement in the Cancer and Sexuality study you have already participated in through the completion of a questionnaire.

## Who is undertaking the research?

This research is being undertaken by Chloe Parton, a PhD Candidate within Gender Culture and Health Unit: Psyhealth, School of Psychology, University of Western Sydney. The supervisory panel for this research are: Associate Professor Janette Perz (primary supervisor), Dr Emilee Gilbert and Professor Ian Wilson.

## What is the purpose of the study?

The purpose of this PhD research is to explore experiences of sexual embodiment for women with cancer. This includes how women experience the changes to their bodies as a result of cancer and the impact of these on their sexuality.

#### Do you have a choice?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect you adversely in any way. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

## Who will be invited to participate?

You will be invited to participate in this research if you are a woman who has experienced cancer. The research is aiming to explore sexual embodiment

across a range of cancer experiences including different age groups, types of cancer, and stages of cancer.

#### What will happen on the study?

If you are willing to take part, you will be asked to attend an individual interview with the PhD Candidate. During the interview the PhD Candidate will ask you questions about changes to your body you have experienced as a result of cancer, how you have felt about these changes to your body and their impact on you and how you experience your sexuality. The interview should take no more than one hour. There is a possibility you may be invited to participate in a follow up interview. The aim of this second interview would be to talk about any experiences that may have been raised by reflection on the first interview. This second interview would also allow us to talk about any changes that may have occurred for you over time. These discussions will be audio taped to allow us to go over what is said in detail afterwards. This discussion will be strictly confidential.

#### Are there any risks?

Discussing sexuality and intimacy post-cancer can be difficult and has the potential to raise personal concerns. The researchers involved in this PhD project are particularly sensitive to the ethical issues in the project, and will ensure the ethical conduct of all aspects of the research. If you find any of the questions unsettling, or find that they raise issues you had not previously considered, please feel free to contact the PhD Candidate, Chloe Parton on 1800 19 20 02 or c.parton@uws.edu.au, or her supervisor, Associate Professor Janette Perz on (02) 9772 6512 or j.perz@uws.edu.au. Alternatively, if you do not want to speak to someone within research project, you can contact the NSW Cancer Council Helpline on 13 11 20, who can provide independent advice and counselling.

#### Are there any benefits?

This PhD research will provide in-depth knowledge to further understand the experiences and needs of women with cancer in the sphere of intimacy and sexuality.

#### Confidentiality / Privacy

Any identifiable information that is collected about you in connection with this study will remain confidential. Only the named researchers and personnel relevant to the study will have access to your interviews that will be held securely at the University of Western Sydney. Throughout the study, everything you say or write on the forms will be strictly confidential. In publications arising from the research, all information will be summarised and no one will be mentioned by name.

Will taking part in this study cost me anything, and will I be paid? Participation in this study will not cost you anything. You will be reimbursed for your time and reasonable travel expenses to the amount of \$25 per interview.

#### What happens with the results?

If you give us your permission by signing the consent form, your participation in an interview will contribute to the results of this research that will form the basis of a PhD thesis. We plan to discuss the overall results with the partner organizations which co-funded the research, in order to facilitate broader understanding of the impact of cancer on sexuality. We also intend to publish the results in peer-reviewed journals, and present them at conferences or other professional forums. In the thesis and any other publications, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

#### Complaints

This study has been approved by the University of Western Sydney Human Research Ethics Committee (Study re. H6545). If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact: the Ethics Committee through the Research Ethics Officer (tel: 02 4736 0883; fax: 02 4736 0013; email: humanethics@uws.edu.au.

#### **Contact details**

When you have read this information, if you would like to take part in the interviews, please contact the PhD Candidate, Chloe Parton, on 1800 19 20 02 or c.parton@uws.edu.au. If we don't hear from you, Chloe will follow up this letter after two weeks with a phone call to see if you are still interested in participating in an interview. If you have any queries, or would like to know more at any stage, or if you have any problems while on the study, please do not hesitate to contact Chloe. Alternatively, you can contact Associate Professor Janette Perz (Supervisor) on (02) 9772 6512 or j.perz@uws.edu.au.

Thank you for taking the time to consider this study.

This information sheet is for you to keep.

# **Appendix 3: Participant Consent Form**

## PARTICIPANT CONSENT FORM

Study Title: Women's Experiences of Sexual Embodiment in the Context of Cancer

## **CONSENT TO PARTICIPATE IN RESEARCH**

Name of Researcher: Chloe Parton (PhD Candidate, School of Psychology, University of Western Sydney)

Primary Supervisor: Associate Professor Janette Perz (School of Psychology, University of Western Sydney)

- I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.
- 2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by \_\_\_\_\_\_\_ ("the researcher") and I, being over the age of 18 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.
- 3. I acknowledge that I have been given time to consider the information and to seek other advice.
- 4. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.
- I acknowledge that this research has been approved by The University of Western Sydney Human Research Ethics Committees.
- I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.
- 7. I understand my identity will not be disclosed to anyone else or in publications or presentations.

Name of participant:	
Signature of participant	 
lato:	