Talking about Sexuality and Intimacy: Health Professional Sexual Communication in the Context of Cancer and Palliative Care.

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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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Abstract

It is now well established that cancer and cancer treatments often have detrimental impacts on the sexual wellbeing and relationships of palliative patients and their partners. Consequently, most palliative cancer patients have reported wanting the opportunity to discuss the impact of these sexual and intimate changes with health professionals. However, whilst most health professionals working in the field of cancer consider sexual communication and information provision to be important, they have reported that in practice, this rarely happens. Previous research has identified a number of personal and structural barriers to such sexual communication; however discursive barriers have received less attention. Equally, there has also been an absence of research examining palliative cancer care health professionals’ knowledge of the potential sexual and intimate concerns of palliative patients and their partners, and how they may respond to these concerns.

This study examined how personal, structural and discursive barriers may interact to facilitate or limit health professional and patient or partner sexual communication in the context of palliative cancer care. A material-discursive-intrapsychic analytical framework was adopted, situated within a critical realist epistemological paradigm. Thirty palliative cancer care health professionals, including physicians, nurses, psychologists, bereavement counsellors and social workers, took part in semi-structured individual interviews. The interview accounts were analysed using thematic discourse analysis.

Overall, the participants identified a broad range of physical, psychological and relational changes in relation to sexuality that could potentially be experienced by palliative cancer patients and their partners. Health professionals reported that they most often responded to the sexual and intimate concerns of palliative patients
and their partners by providing emotional support, by facilitating couple communication, and through encouraging non-sexual expressions of intimacy. However, a number of challenges to sexual communication with palliative patients and their partners were identified. In particular, it was found that normative discourses around heterosex, gender, age, illness and dying contributed to sexuality being positioned as irrelevant or inappropriate for particular groups of patients and partners. It was also found that the biomedical discourse shaped the material structure of clinical settings problematically, particularly in relation to time and privacy constraints. Participants also reported that sexual expression by patients and partners was largely considered to be ‘inappropriate’ within hospital and hospice settings, and thus not supported by many hospital and hospice staff. Further, it was identified that these discursive and material barriers allowed palliative care health professionals opportunity to take up subject positions which could excuse them from addressing sexual concerns.

The implications of these research findings suggest that interventions to improve health professional sexual communication in the context of palliative cancer care could focus on challenging sexual myths, and on improving the material constraints of clinical settings. It is also argued that further research is needed to explore how discursive factors, along with intrapsychic and material factors, shape how palliative cancer patients and their partners experience post-cancer sexual and relational changes.
Prologue

Actually, it’s [sexuality] something that I think a lot of people are nervous about, they shy away from it. And I think it’s a good thing it’s being brought up…I really do because it’s part of who we are. . .yeah, it’s not a dirty secret that everyone should be hiding away.


The above participant account is typical of many palliative care patients and partners, who report that sexuality remains important at end-of-life, and that they wish to talk with palliative care health professionals about the impact of terminal illness on their sexuality (Taylor, 2014). Six years after Lemieux et al.’s (2004) paper was published, I had the opportunity to work on my honours thesis on cancer, palliative care and sexuality research. In this capacity I began reading, and soon became surprised and curious about how little of this research had been conducted in the area of palliative care. This is despite the fact that the few studies in palliative care, cancer and sexuality that had been published (i.e. Ananth, Jones, King, & Tookman, 2003) found that palliative patients experienced greater sexual difficulties compared to those with early stages of cancer.

As I progressed in reading this research literature, further questions began to arise, including: What sort of sexual and intimate expression might be possible or desired at the end-of-life? How might the experience of anticipatory grief impact the sexual and intimate relationships of couples? How does advanced cancer affect sexual and intimate expression? I further noted that little research had examined whether palliative care health professionals recognised the potential sexual and
intimate difficulties of patients or partners, or explored what support they were able to offer.

Further to this, I had also read about how the palliative care model evolved in part as a reaction to the limitations of the medical model (Lewis, 2007). In other words, the palliative care discourse emphasises the need for health professionals to respond to all forms of suffering - whether physical, psychological, relational, or spiritual in nature - rather than the focus being primarily on physical forms of suffering or illness (Mino & Lert, 2005; Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008). Equally, palliative care is an approach that is directed towards improving and preserving quality of life and the dignity of patients when cure is no longer possible (Chochinov, 2002). When reading the cancer and sexuality research literature, I read reports that medically-trained health professionals (mainly from non-palliative care settings) were more likely to address the ‘medicalised’ aspects of sexuality, such as sexual functioning and fertility, often to the exclusion of the emotional and relational sexual concerns that patients wanted addressed (Hordern & Street, 2007a). Subsequently, I wondered whether medically-trained health professionals working within a palliative care paradigm may be better supported or guided to respond to all forms of suffering as it relates to sexuality. Conversely I also queried whether broader social taboos around sexuality, dying and older age (Nyatanga, 2012) may prevent palliative care health professionals from considering the sexual and intimate needs of palliative patients, regardless of their broad mandate in patient care.

Taken together, these questions and my developed interest in the topic of palliative care and sexuality facilitated me to put in a submission to undertake PhD
research in this area, with the support of my present supervisory panel. I was fortunate to be able to commence this research in the following year.

Shortly after I commenced this Doctoral research, several acquaintances who asked about my topic of research questioned how sex could be physically possible or desired at the end-of-life. This question was typically asked as they recalled parents or grandparents who had experienced terminal cancer. These questions furthered my interest and thoughts about the research, as I speculated that perhaps this difficulty in imagining palliative care patients having sexual desire was because ‘sex’ was constructed as sexual intercourse and performance (McPhillips, Braun, & Gavey, 2001), of which palliative patients were deemed physically incapable of due to advanced illness. I accordingly thought about how these taken-for-granted constructions of sex may be limiting people, including palliative care health professionals, from recognising the sexual needs of palliative patients and their partners. Perhaps palliative care health professionals may not consider the other ways that palliative cancer patients and partners may be able to practice sexuality or intimacy, or they may not be given opportunity to talk about the loss of sexuality in their lives following cancer?

These are some of the questions and thoughts that initially brought me to undertake this Doctoral research, and which came to the fore early on as I commenced my study - although more questions arose over the course of reading and data collection, that are documented and addressed throughout this thesis.
Chapter One: Introduction

This thesis will examine health professionals’ experiences of communicating about, and responding to, the sexual and intimate needs of palliative care cancer patients and their partners. In particular, this thesis seeks to contribute to knowledge on how palliative care health professionals negotiate various cultural constructions of sexuality, age, illness, and dying that may either facilitate or delimit their capacity to respond to these needs. This thesis will also evaluate how personal and structural factors, such as feelings of embarrassment and a lack of privacy within clinical settings, may also make sexual communication difficult.

In this introductory chapter, I will first provide an overview of the prevalence of cancer in Australia, and the number of individuals using palliative care services who have a cancer diagnosis. I will then provide a background to the study, which will include defining the terms sexuality and intimacy, and examine why sexual communication is an important part of cancer and palliative care. Following on, I will present the research aims and questions, and explain the epistemological and theoretical approach that I adopt in this thesis. Finally, I will conclude this introductory chapter by outlining the overall argument of the thesis.

Sexuality, Intimacy, Cancer and Palliative Care: An Area of Unmet Need

Cancer is a significant health issue in Australia, with 123,920 Australians estimated to have been diagnosed in 2014 (AIHW, 2014). Cancer is also one of the leading causes of death in the developed world (Jemal et al., 2011); in Australia it is estimated that it causes 3 out of every 10 deaths (AIHW, 2014). Palliative care is an approach which aims to improve the quality of life of individuals who have a life-threatening illness (World Health Organisation, 2015), and in Australia, palliative care services are offered in most settings where health care is provided, including
hospital and hospice settings, and in the community, such as the patient’s home (AIHW, 2012). It has been estimated that 50 – 90% of cancer patients are referred to palliative care services (AIHW, 2012; Currow et al., 2008), with 59.4% of those receiving palliative care during 2009-2010 having had a principal diagnosis of cancer (AIHW, 2012). This proportion rose to 75.8% when patients received primary treatment for a non-cancer related principal diagnosis, such as kidney failure, yet also had a concurrent cancer diagnosis (AIHW, 2012). Cancer patients, therefore, constitute the highest proportion of those receiving palliative services.

Previous research has established that most people with cancer, including those in palliative care, consider sexuality and intimacy to be an important part of their quality of life (Ananth et al., 2003; Lemieux et al., 2004). It is well established that sexuality, and the ability to experience intimacy, is important to a person’s sense of self and psychological wellbeing, with the expression of sexuality and intimacy being an important aspect of quality of life. As the World Health Organisation (2004) has pointed out:

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. (p. 3).

In the context of the present study, intimacy is as important as sexuality. Intimacy has been defined as “a quality of a relationship in which the individuals must have reciprocal feelings of trust and emotional closeness towards each other and are able to openly communicate thoughts and feelings towards each other” (Timmerman, 1991, p. 28). In a palliative context, intimacy has been described as the ability of
individuals to express their emotional needs through physical intimacy and to communicate feelings of love and tenderness towards each other (Gilley, 1988; Stausmire, 2004).

Sexuality and intimacy are often disrupted post-cancer, leading to changes to physical, emotional, and relational sexual wellbeing, and diminishing overall quality of life (Ananth et al., 2003; Lemieux et al., 2004; Perz, Ussher, & Gilbert, 2014; Ussher, Perz, & Gilbert, 2015). For example, physical changes caused by cancer and cancer treatments include symptoms such as nausea, pain, fatigue, decreased sex drive, hot flushes and incontinence; all of which can limit the capacity of patients and their partners to engage in sexual activities (Gilbert, Ussher, & Perz, 2011; Hordern & Currow, 2003). Further, cancer-related changes to the body, including scarring, hair loss, weight gain or loss, and loss of control over bodily functions, can also lead to feelings of embarrassment and sexual unattractiveness (Lawton, 2000; Muir, 2000), and can negatively impact the gendered identity of patients (Gilbert, Ussher, & Perz, 2012; Parton, Ussher, & Perz, 2015). These changes are discussed in more detail in Chapter Two, which reviews the research literature.

While a significant amount of research has been conducted in the area of cancer and sexuality, there has been much less of a focus on changes to sexuality in palliative cancer care settings (Lemieux et al., 2004; McClelland, 2015; Mercadante, Vitrano, & Catania, 2010). However, the few studies that have examined the sexual wellbeing of advanced cancer or palliative patients have consistently found that this population experiences greater disruptions to their sexual wellbeing than patients with early stage cancer. For example, one study, that looked at the impact of cancer on sexual function, found that palliative cancer care recipients reported a lower quality of life, greater emotional distress, and higher levels of sexual dysfunction.
than people with early stage cancer (Ananth et al., 2003). Furthermore, in addition to facing greater sexual difficulties than those with early stage cancer, palliative patients and their partners may also experience sexual and intimate difficulties that are unique to the palliative context. For example, little is known about how couples may negotiate the experience of anticipatory grief, which often comes with acknowledgement of the impending loss of the patient, and how this may impact on the sexual and intimate practices shared by the couple (Redelman, 2008). Therefore, there is a need for research to give greater attention to understanding the sexual and intimate needs of palliative cancer patients and their partners, and to examining how their sexual wellbeing may be supported.

In the light of this research, it has been argued that health professionals should play a role in providing opportunity for patients and partners to discuss changes to sexuality and intimacy after cancer, offering practical support and advice (Hordern & Street, 2007b; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Opening communication about sexuality may allow, for example, for the experiences of patients and partners to be validated, and may give couples’ permission to explore how the patient’s illness has affected their sexual practices and identities (Hordern & Currow, 2003; Stausmire, 2004). Raising the issue of sexuality and intimacy in a palliative context may also allow for an exploration of how the profound impact of the patient’s imminent death may affect their intimate relationship (Cagle & Bolte, 2009; Stausmire, 2004).

Research has shown that many palliative care patients report wanting to discuss issues of sexuality with health professionals (Ananth et al., 2003), and that many patients believe the onus should be on health professionals to raise the issue of sexuality (Lemieux et al., 2004). Equally, recent research has demonstrated that the
majority of health professionals working in cancer care agree that sexuality is an important aspect of the patient’s quality of life, and that it is important to discuss sexual issues as part of their holistic care (Haboubi & Lincoln, 2003; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Further to this, many health care professionals agree that it is a responsibility of their role to give patients permission and opportunity to discuss their sexual concerns with them (Magnan, Reynolds, & Galvin, 2005; Saunamaki, Andersson, & Engstrom, 2010).

Nevertheless, despite this recognition, it has been found that the majority of health professionals avoid raising issues of sexuality with cancer patients and their partners, due to a range of personal and structural barriers (Algier & Kav, 2008; Hordern & Street, 2007c). These include, a perceived lack of knowledge and feelings of incompetence in their ability to address this issue (Hautamäki, Miettinen, Kellokumpu-Lehtinen, Aalto, & Lehto, 2007; Magnan et al., 2005), and a lack of privacy, as well as time constraints, within clinical settings (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013; Wiggins, Wood, Granai, & Dizon, 2007). However, in addition to these structural and personal barriers, cultural constructions of dying, illness, aging and sexuality may potentially also impact health professional sexual communication, and may lead health professionals to position palliative patients, in particular, as ‘not needing to know’ about sexuality and intimacy. For example, the construction of older people as being uninterested in sexual practices has been found to prevent health professionals from raising sexuality with older patients (Gott, Galena, Hinchliff, & Elford, 2004; Gott, Hinchliff, & Galena, 2004; Hordern & Street, 2007c).

Most of the current cancer and sexuality research has focused on examining barriers to health professional communication. There has, in contrast, been a paucity
of research which has examined what enables health professionals to talk about sexuality (Marie, 2013). That is to say, what sexual and intimate issues health professionals may recognise in patients and their partners, and how they may respond to these issues. Further, although cultural constructions may also impact health professional sexual communication, there has been an absence of focus on discursive constructions of cancer, aging, sexuality, illness and dying in much of the existing cancer and sexuality research. Consequently, further research is needed to explore how discursive barriers may interact with personal and structural barriers to enable or limit health care professional communication around sexuality and intimacy (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

As such, this thesis seeks to address these gaps, by adopting a theoretical framework that will enable examination of how these structural, personal, and cultural factors together work to either enable or delimit health professional communication about sexuality and intimacy in the context of cancer and palliative care. In the section that follows, I will outline the research aims addressed in this thesis and provide detail on the theoretical approach that I am adopting.

**Focus of the Current Study**

The aim of this research study is to examine how health professionals construct and communicate about issues of sexuality and intimacy with people with cancer who are receiving palliative care, and their partners. The following research questions will address this research aim:

How do health care professionals construct sexuality and intimacy in the context of palliative care and cancer?

What are health care professionals’ experiences of communicating about issues of sexuality and intimacy in the context of palliative cancer care?
How do discursive constructions of sexuality, aging, medicine, illness and dying shape the communication practices of health care professionals in the context of palliative cancer care?

This study adopts a qualitative methodology, in which semi-structured interviews were conducted with thirty health professionals who work with palliative oncology patients. Participants were sampled from the following four health professional groups: physicians, nurses, social workers, and psychologists and counsellors. The interview data were analysed using a thematic discourse analysis, which drew on the theoretical approach outlined below, and which will be discussed in further detail in Chapter Three.

**Theoretical Approach**

This thesis will employ a material-discursive-intrapsychic analytical framework (Ussher, 2000), drawing specifically upon Foucault’s (1975, 1976) work on discourse, and situated within a critical realist epistemological approach (Bhaskar, 2011). Critical realism has been viewed as an epistemological standpoint which bridges the divide between constructionist and realist perspectives; by acknowledging the materiality of the world, yet recognizing that our experiences and knowledge are mediated through culture and language (Bhaskar, 2011; Ussher, 2000).

This section will first look at how constructionist and critical realist epistemological paradigms have drawn on the notion of discourse to conceptualise and examine how our knowledge and experience are shaped through social processes. I will then discuss where constructionist and critical realist paradigms depart, as I acknowledge the role of materiality in also shaping our knowledge and experience. At this point, I will then explain how the material-discursive-intrapsychic
analytical framework is compatible with a critical realist framework, and can be used to explore the material, discursive, and intrapsychic factors that together shape the experiences, knowledge, and practices of health professionals in relation to sexual communication, cancer, and palliative care.

Knowledge and experience as mediated through discourse.

Both constructionist and critical realist approaches have allowed researchers to acknowledge and examine how social processes, which are historically and culturally specific, are fundamental in constructing our knowledge of the world and our experiences (Bhaskar, 2011; Burr, 2003). These paradigms also encourage us to be critical of our ‘taken-for-granted’ knowledge of the world and ourselves, and invite examination of how “social, moral, political and economic institutions” (Gergen, 1985, p. 267), such as educational, medical, psychiatric, and psychological institutions, shape our social reality, and have implications for our behaviour and subjectivity.

Poststructuralist theorists, and in particular, Foucault’s (1976) work on discourse, have provided a framework for understanding how such institutions create knowledge and produce social action through language. According to Foucault, our sense of self, and our subjectivity (how we think and feel) is formed through discourse, and our social practices and talk also work to actively (re)produce discourse (Foucault, 1976; Willig, 2008). A fundamental premise in poststructuralist theory, accordingly, is that language does not merely reflect the world, but rather, through shared cultural assumptions about words, language can be drawn upon to actively construct our understanding of reality (Willig, 2008). For Foucault (1963, 1976), discourses are systems of knowledge, mainly produced through institutions, which shape and teach us morality, ‘truth’ and social practices. Discourses are
historically and culturally specific, and as such are not fixed, but rather are always in a state of change (Foucault, 1972). Subject positions, which are made available through discourse, provide possibilities for the constitution of our subjectivity; shaping and regulating our identities, practices, feelings, and the meanings we give to the world (Davies & Harre, 1990; Gavey, 1989). Multiple discourses, and therefore subject positions, are available and can offer sometimes competing and contradictory views on how we give meaning to the world. However, dominant discourses are those which produce privileged versions of our social world, with the knowledge they produce often accepted as ‘common sense’ (Foucault, 1963). Consequently, the presence and workings of these discourses may not be ‘visible’ to many, which thus makes these dominant discourses difficult to challenge (Gavey, 2005).

Foucault’s (1975) concept of ‘disciplinary power’ has provided instruction on how discourse regulates the practices and subjectivity of the individual. Regulation of an individual’s practice is not only enforced externally by institutions, but can also be regulated on the level of the individual, who, “through a myriad of techniques of observation, measurement, reward, and punishment, pressure is brought upon people to strive for conformity” (Gavey, 2005, p. 87); or, as Foucault refers to it, the “power of the norm” (Foucault, 1975, p. 184). Using the metaphor of the panopticon - an architectural prison design that allows all prisoners to be observed without the prisoners knowing whether and when they are being watched; therefore effectively ensuring that prisoners self-regulate their behaviour at all times - Foucault (1975) described how individuals come to self-surveillance and internally regulate their subjectivity and behaviour to practice in accordance with social norms. Thus, discipline not only comes from external authorities, but also occurs, and is enforced, within us.
Yet, whilst dominant discourses often constrain us to act and experience the world in a particular way, individuals are not passive subjects of discourse. Rather, as Foucault (1976) argued in his later work:

We must make allowance for the complex and unstable process whereby discourse can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an opposing strategy. Discourse transmits and produces power; it reinforces it, but also undermines it and exposes it, renders it fragile and makes it possible to thwart it (p. 101).

In other words, the ‘exposure’ of the existence and workings of a particular discourse can create possibilities for the formation of alternative discourses that counter it.

Thus, individuals are able to exercise agency, and resist dominant discourses, by taking up subject positions made available by alternative discourses (Gavey, 2005). Equally, however, individuals may also put particular discourses ‘to use’, and accordingly exercise agency by adopting or assigning to others particular subject positions, when these positions work to serve their interests and legitimate certain individual practices (Davies & Harre, 1990; Gavey, 1989). As such, whilst discourse may function to dominate and constrain possibilities for our behavior and subjectivity, individuals are also active negotiators of discourse; able to both resist, or use, discourse and the subject positions it makes available to serve their interests and justify their practices.

These poststructuralist theorisations of how discourse and language both constitute, and are reproduced by, our practices, talk, and subjectivity are central to the analysis presented in this thesis. In particular, these concepts will enable examination of how dominant discourses of sexuality, medicine, illness, and dying
may potentially limit or open up possibilities for sexual communication and practice. Conjointly, these concepts will also allow exploration of how health professionals may actively negotiate these discourses by taking up, or placing upon others, the various subject positions made available through discourse; and the consequences this positioning has for health professional sexual communication and practice. Finally, it will also provide a way to examine how discourse is both produced and reflected in health professionals’ talk, and the implications this also has for whether health professionals are able to recognise and respond to the sexual needs of patients and their partners.

A Material-Discursive-Intrapsychic analytical approach: Acknowledging materiality and the intrapsychic.

Whilst both constructionist and critical realist epistemological paradigms have enabled researchers to examine how practices and subjectivity are shaped through discourse, constructionist approaches - in contrast to critical realism- have been criticised for ignoring embodiment and the materiality of the world (Cromby & Nightingale, 1999). In particular, in the context of health and illness, it has been argued that constructionist approaches have not adequately given consideration to how practices and emotional wellbeing are also shaped by the materiality and functioning of the body, the materiality of illness, and by the structural constraints of health care settings (Sims-Schouten, Riley, & Willig, 2007; Williams, 2003; Yardley, 1996).

In contrast, critical realism recognises that the body exists independently of discourse; that “they [bodies] are lumpy, smelly, messy, unreliable and ultimately destined to self-destruct” (Cromby & Nightingale, 1999, p. 11), and acknowledges that any material changes to the body can impact on a person’s emotional wellbeing.
and relationships. At the same time, critical realism also acknowledges that the material body always sits in relation to cultural discourses; both inscribed with discursive meanings, and performing discursive acts (Ussher, 2008; Weatherall, Potts, & Gavey, 2004). For example, it is through embodied acts - including how one speaks, the use of cosmetics, hair styles, and bodily postures - that women and men perform feminine and masculine gendered identities, and thereby reproduce socially ingrained sexual scripts that establish and maintain dichotomised sexual differences between men and women (Butler, 1990). Consequently, any material changes to the body that impact how a person can present their gendered identity are likely to have implications for their emotional wellbeing and their self-positioning within discourses of gender and sexuality. This example demonstrates the importance and usefulness of adopting an analytical approach that enables consideration of how material and discursive factors together shape a person’s experience (Yardley, 1996).

It has subsequently been argued that material-discursive analytical approaches would benefit further by also examining intrapsychic factors, and their inter-related role in also shaping a person’s experience and practice (Ussher, 2000, 2004). For example, it is also worthwhile to consider how a person’s behaviour and subjectivity are also shaped by their psychological interpretations of previous experiences, in combination with material and discursive influences (Ussher, 2000).

Accordingly, a material-discursive-intrapsychic analytical approach, compatible with a critical realist paradigm, allows us to recognise and examine the ongoing interaction between the material, intrapsychic, and discursive worlds, in shaping an individual’s subjectivity and practices (Gilbert et al., 2011; Gilbert et al., 2013; Ussher, 2000). Within this theoretical model, materiality refers to “…factors that exist at a corporeal, societal, or institutional level – factors that are traditionally
at the centre of biomedical or sociological accounts” (Ussher, 2000, p. 219). For the purposes of this thesis, materiality might include examining the impact of the structure of health care settings, including privacy and time constraints, in influencing health professional sexual communication and practices. It might also include looking at health professionals’ experience of working with, patients and partners who face the ‘reality’ of the patient’s cancerous and life-limited body, and how post-cancer bodily changes shape the sexual wellbeing of patients and couples. The intrapsychic refers to factors that occur at “…the level of the individual and psychological” (Ussher, 2000, p. 220). For this thesis, this might include examining the impact of health professionals’ interpretations of past experiences where they either have or have not practiced sexual communication with patients. It might also include examining how they feel about communicating about sexuality, which may encompass feelings of embarrassment and vulnerability, and how these intrapsychic experiences impact their willingness to communicate about sexuality. Lastly, the discursive refers to consideration of the “…social and linguistic domains” (Ussher, 2000, p. 219), which in this thesis might include an examination of how health professionals negotiate medical and cultural constructions of sexuality, age, illness and dying, and how these discourses may potentially shape their knowledge, practice, and talk in relation to sexuality and intimacy.

Whilst these material, intrapsychic, and discursive factors can be discussed separately, a material-discursive-intrapsychic approach acknowledges that experience is constructed by the ongoing inter-relationship between these factors (Ussher, 2000; Ussher, Hunter, & Cariss, 2002). As such, this approach allows for an analysis of how particular discourses may shape the material structures of clinical settings, as well as health professionals’ understandings of the cultural meanings
attached to patient’s bodies and sexuality. Equally, this approach will also allow for consideration of how the material structures of clinical settings may shape the discursive practices of health professionals. In summary, a material-discursive-intrapsychic approach will allow for an examination of how material, intrapsychic and discursive factors may interact to enhance or delimit health professional communication and practice in relation to sexuality and intimacy.

**Argument of the Thesis**

This thesis is presented in the following way. In Chapter Two, I provide a critical review of previous research which has examined the material and intrapsychic changes to sexuality and intimacy post-cancer, as well as in palliative care. This will include a discursive critique of this literature, in which I will examine the various discourses that produce knowledge in the area of cancer, sexuality and palliative care. In this discursive critique I will also discuss previous research that has examined discursive changes to sexuality and intimacy post-cancer, and argue that the material, intrapsychic and discursive factors must be considered together in order to understand the post-cancer sexual and intimate needs of patients and their partners, rather than considered in isolation. Finally, this second chapter will critically review previous research that has examined health professional communication about sexuality, and will identify material, intrapsychic and discursive factors that may potentially shape palliative care health professionals’ communication about sexuality, which is the focus of this thesis.

Chapter Three examines the methodology that was adopted in this study. In this chapter I will describe the research design, recruitment procedure, and process of data collection. In the form of ‘pen portraits’, I will also introduce the sample of
health professionals who were interviewed. A critical realist informed thematic discourse analysis was conducted, and will be discussed in this chapter.

In Chapter Four, Five and Six I examine the findings of the thematic discourse analysis, and discuss and interpret these findings using existing research and theory. Chapter Four discusses findings which relate to health professionals’ recognition of the sexual and intimate changes that occur post-cancer and in the context of palliative care, and their successes in responding to these changes. Following on from this chapter, the remaining two analysis chapters will move on to largely focus on, and discuss, the challenges that palliative care health professionals reportedly experienced in regards to addressing sexuality and intimacy. In this vein, Chapter Five discusses findings relating to the discursive patient-centred barriers that health professionals experienced in regards to addressing sexuality and intimacy. In particular, Chapter Five includes an assessment of the subject positions health professionals took up and placed on patients and their partners, and the implications that this positioning had for whether health professionals recognised or responded to patients’ and partners’ sexual and intimate needs. In Chapter Six I discuss how the biomedical discourse shaped and constrained the capacity of medically-trained health professionals to respond to the sexual and intimate needs of patients. In this chapter I also explore the discursive constructions of hospital, hospice and community care settings in which palliative care is provided, and discuss the implications for health professional practice and communication in relation to sexuality and intimacy.

Finally, in Chapter Seven, the conclusion, I will review the research aims and overall findings of the study, and examine the implications of these findings for palliative care health professionals’ practice in regards to sexual communication. I
will conclude this chapter by discussing the limitations of this research, and by outlining recommendations for future research.
Chapter Two: Literature Review

This chapter will present a critical review of research studies within two broad streams of research within the area of sexuality, cancer and palliative care. Firstly, I review studies which examined the post-cancer changes to sexuality and intimacy experienced by patients and partners, including those receiving palliative care. It is important to examine these studies because they (re)produce and legitimise particular constructions of sexuality and cancer, and accordingly shape oncology and palliative care health professionals’ knowledge surrounding when and how they should raise and respond to issues of sexuality and intimacy. The second area of research which I review includes studies which have examined health professionals’ communication about sexuality and intimacy in the context of cancer and palliative care.

This chapter will be structured as follows. Firstly, I will present an overview of the material, intrapsychic and relational, and discursive changes to sexuality and intimacy that cancer patients and their partners can experience. This will be followed by a discursive critique of the biomedical and psychological literature on cancer and sexuality, where it was found that most of the existing cancer and sexuality literature uncritically drew on discourses of heteronormativity and biomedical constructions of sexuality, which meant that the sexual needs and concerns of particular groups of cancer patients were not considered by researchers. Finally, I will review and critique the studies which have examined health professional communication about sexuality in the context of cancer and/or palliative care, where it was found that the majority did not examine sociocultural barriers to health professionals’ post-cancer sexual communication. This critique of the health professional communication literature will end with an overview of the sociocultural constructions of illness, dying, age,
and sexuality which may also impact health professional communication in the context of cancer and palliative care.

**Changes to Sexuality and Intimacy in the Context of Cancer and Palliative Care**

**Material changes to sexuality and intimacy.**

It has now been well established that that most people with cancer experience physical disruptions to their sexual functioning, caused by all cancers and related treatments (Speer et al., 2005; Vitrano, Catania, & Mercadante, 2011; Zebrack, Foley, Wittmann, & Leonard, 2010). These changes include post-cancer decreases in sexual interest and desire (Broeckel, Thors, Jacobsen, Small, & Cox, 2002; Monga, 2002; Rossen, Pedersen, Zachariae, & von der Maase, 2012) and reductions in frequency of coital sex (Biglia et al., 2010; Perz et al., 2014; Vitrano et al., 2011). Further, when patients do engage in coital sex, they often report lower levels of sexual satisfaction and pleasure (Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999; Ussher, Perz, & Gilbert, 2015), and experience greater orgasmic difficulties (Aerts et al., 2015; Archibald, Lemieux, Byers, Tamlyn, & Worth, 2006), when compared to their pre-cancer experience, or to those without cancer. Fewer studies have examined how sexual functioning is affected in those with advanced or terminal cancer (McClelland, 2015; Mercadante et al., 2010), despite many palliative care patients reporting that sexuality continues to remain an important part of their quality of life (Lemieux et al., 2004). However, these few studies have found that patients with advanced cancer report greater levels of sexual dysfunction than those with early stage cancer. For example, one study found that palliative cancer care patients experienced significantly more sexual problems than people with early stage cancer, as well as reporting a lower quality of life, greater emotional distress, and higher levels of sexual dysfunction (Ananth et al., 2003). Similarly, a study conducted with
those with advanced cancer found that many participants reported a significant
decrease in sexual activities and lower levels of sexual satisfaction and effectiveness
of sexual activities post-cancer (Vitrano et al., 2011). Clearly, sexuality is also
important to palliative care patients, despite the fact that this section of the cancer
population has been largely ignored by the research literature to date, pointing to the
need for further research in this area.

The following section will examine some of the physical changes caused by
cancer and cancer treatments which can disrupt patients’ sexual functioning and
engagement in sexual practices. As multiple disturbances to sexual functioning are
concomitant, it can be difficult to identify isolated ‘cause and effect’ relationships for
sexual dysfunction (Mercadante et al., 2010). Thus, whilst here I will identify and
discuss singular physical causes to sexual dysfunction, it is important to recognise
that often these physical factors operate in unison with other physical factors.

Fatigue, which often accompanies cancer treatments such as chemotherapy
and radiation, can contribute to lower levels of sexual interest or desire (Cort,
Monroe, & Oliviere, 2004; Mercadante et al., 2010; Schwartz & Plawecki, 2002;
Ussher, Perz, & Gilbert, 2012). Fatigue can also occur with depression, which
together can accentuate its impact on reducing sexual desire (Audette & Waterman,
2010; Perz et al., 2014). Cancer-related fatigue is recognised as a frequent concern
amongst palliative patients, with palliative patients often reporting this symptom as
having the greatest detrimental effect on their quality of life, compared to other
symptoms (Narayanan & Koshy, 2009). In one of the few studies examining the
sexuality of palliative care patients, some participants reported engaging in less coital
sex due to a lack of energy (Lemieux et al., 2004). However, the participants
reported that sexuality still remained important to them, and it was found that they
placed greater importance on non-coital forms of sexual expression, such as touch and emotional connectedness. Further research is needed to establish the extent to which fatigue might disrupt the sexual practices and sexual desire or interest of palliative patients.

Nausea and vomiting has also been found to reduce sexual activity in cancer patients (Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004; Fobair et al., 2006) and can also lead to feelings of sexual unattractiveness. Nausea and vomiting is a common and debilitating symptom experienced by palliative care patients, and therefore a significant cause of distress in this population (Rhodes & McDaniel, 2001). Nausea can be caused by chemotherapy, a treatment that palliative patients may continue to receive to treat other symptoms, or by gastrointestinal obstruction (Rhodes & McDaniel, 2001). In a study of patients with advanced cancer, the prevalence of nausea was highest for those with gynaecological (42%) and stomach (36%) cancers, and those experiencing dyspnea from lung cancer (46%) (Vainio & Auvinen, 1996). Nausea is therefore likely to limit the capacity of a number of palliative patients in expressing sexuality and intimacy.

Pain can also negatively impact upon patients’ sexual functioning and engagement in sexual practices, in particular, sexual intercourse (Monga, 2002), and can be experienced regardless of cancer type (van den Beuken-van Everdingen et al., 2007). For example, surgical procedures undertaken on the pelvic region or genitals of women due to cancer, as well as undergoing systemic therapies such as chemotherapy and radiation, can cause dyspareunia (Gilbert et al., 2011), a shortened or narrowed vagina (Jensen et al., 2004), and decreased lubrication (Can et al., 2008). Further, medical treatments for post-cancer erectile dysfunction, such as intracorporeal injections, can cause pain during an erection, or following orgasm.
Chronic pain can also be experienced in lymphedema, a condition that produces painful swelling of the tissue and fluid retention, which can occur following removal of the lymph nodes (Pieterse et al., 2006). Pain has also been found to have an indirect impact on sexual functioning, with some couples reporting a decrease in the frequency of sexual practices, because the patient has experienced disrupted sleep due to pain (Lindau, Surawska, Paice, & Baron, 2011). In a systematic review, it was found that patients with advanced, metastatic and terminal cancer experience the highest levels of pain (64%), followed by those receiving anticancer treatment (59%), and those who have completed curative treatment (33%) (van den Beuken-van Everdingen et al., 2007). It can be suggested, therefore, that palliative care patients may experience greater disruptions to their engagement in sexual practices due to pain, than those who have survived cancer, or who are in the earlier stages of receiving cancer treatment. In this vein, palliative care patients have reported avoiding coital sex due to fear of pain, or because their partner is fearful of causing pain (de Vocht, Hordern, Notter, & van de Wiel, 2011; Lemieux et al., 2004; McClelland, Holland, & Griggs, 2015). However, further research, examining sexuality in palliative populations, is needed to explore this issue in more depth.

Changes to the sexual organs following cancer and cancer treatments can also render coital sex difficult or impossible, as well as produce altered sensations in these areas (Arrington, 2008; Gilbert, Ussher, & Perz, 2010b). For example, removal of the reproductive organs in women is linked to less frequent engagement in coital sex (Greenwald & McCormkle, 2008). Further, gynaecological cancer treatments, including radical hysterectomy and pelvic radiation, can produce a loss of uterine sensations, sensitivity, and vaginal stenosis and dryness, which can contribute to a
reduction in sexual activity (Kim et al., 2015; Pieterse et al., 2006; Weijmar Schultz & Van de Wiel, 2003). These physical changes to the sexual organs of women have also been observed in patients with advanced cervical cancer (Grangé et al., 2013) and metastatic breast cancer (McClelland et al., 2015), and thus indicate that palliative patients will also be affected by these physical sexual concerns. Women who have received treatment for breast cancer can also experience numbness in breasts which were sensitive before cancer (Gilbert et al., 2010b). For men, erectile dysfunction is commonly experienced following prostate and testicular surgery and radiation treatment (Litwin et al., 1999; Stanford, Feng, Hamilton, & et al., 2000; Tuinman et al., 2010), along with reduced orgasmic sensation (Danile & Haddow, 2011; Rossen et al., 2012). These changes have also been reported in men with advanced prostate cancer (Benedict et al., 2014).

Although much of the research concerning cancer patients and sexual functioning focuses on cancers of the reproductive organs, there is evidence to suggest that cancer patients with other cancers, such as head and neck, bladder, and colorectal cancers, can also experience these changes to their sexual organs (Booth, Rasmussen, & Jensen, 2015; Galbraith & Crighton, 2008; Traa, De Vries, Roukema, & Den Oudsten, 2011). This includes those who have advanced cancer (Perz et al., 2014; Ussher, Perz, & Gilbert, 2015). In particular, systemic treatments such as chemotherapy, radiation and hormonal therapies are likely to produce these changes (Monga, 2002). These findings show that changes to the sexual organs can occur regardless of cancer type or stage. However, given there are few studies examining changes to the sexual organs experienced by those with advanced cancer, more research is clearly needed in this area, and such research could also compare whether
the impact of these changes might differ in any way from those who have early stage cancer.

**Intrapsychic and relational changes to sexuality and intimacy: Patients and partners.**

Physical changes are not the only factor impacting on sexuality after cancer. Cancer patients and their partners also experience a range of intrapsychic and relational changes to sexuality and intimacy, which will be explored in this section. This section will first review findings relating to the intrapsychic sexual changes experienced by cancer patients, which included psychological distress and changes to body image, and I will also discuss how these intrapsychic changes impacted on sexual functioning and wellbeing. The findings relating to the intrapsychic sexual concerns of partners will then be discussed, and this section will then conclude with a review of how couple relationships may be affected in the context of cancer and palliative care.

People with cancer who are experiencing psychological distress are more likely to report sexual dysfunction and other disruptions to their sexuality. In particular, cancer patients with depression have reported lower levels of sexual satisfaction and frequency of sex (Carmack Taylor et al., 2004; Nelson, Choi, Mulhall, & Roth, 2007; Perz et al., 2014; Webber et al., 2011), and lower levels of sexual desire and interest (Holmberg, Scott, Alexy, & Fife, 2001; Lindau et al., 2011; Stilos, Doyle, & Daines, 2008). Additionally, depression has also been linked with dyspareunia, erectile dysfunction, ejaculatory dysfunction and loss of orgasm (Michael & O’Keane, 2000). Conversely, it has also been found that those who experience sexual dysfunction, disruptions to their gendered sexual identity, and sexual practices, can be more likely to experience psychological distress (Gilbert et
al., 2012; Spencer et al., 1999). Therefore, these findings demonstrate that the link between sexuality and depression is bi-directional; depression can contribute to sexual dysfunction, as well as result from sexual dysfunction and disruptions to gendered identity. In relation to the prevalence of psychological distress in cancer patients, a meta-analysis found that 30-40% of cancer patients met criteria for one or more mood disorders, including depression and anxiety (Mitchell et al., 2011). This research found that the proportion was similar across both palliative and non-palliative settings. Therefore, it is likely that a considerable number of cancer patients from all cancer stages may experience difficulties relating to their sexual functioning, linked to their emotional wellbeing.

A number of studies found that sexual unattractiveness and loss of confidence (Jensen et al., 2004), diminished body image (Burns, Costello, Ryan-Woolley, & Davidson, 2007) and fear of rejection (Monga, 2002) can occur following physical changes caused by all cancer and cancer treatments. These alterations can be caused by experiences of disfigurement, which can occur due to scarring and hair loss, as well as body shape changes, which include, loss of limb, weight loss/gain, emaciation, or enlargement of the body caused by lymphedema or steroidal treatments (Fobair et al., 2006; Lawton, 2000; Low et al., 2009).

Although most of the research has examined patients’ experiences of post-cancer sexual changes, some studies have examined the impact that these changes have on the sexuality of partners. In these studies, partners have reported a range of concerns, which include, feeling sexually unattractive or undesirable due to the cessation in sex (Sanders et al. 2006); experiencing guilt for having sexual needs when their partner is ‘suffering’ cancer and cancer treatments (Gilbert, Ussher, & Hawkins, 2009; Hawkins et al., 2009); and fear of causing their partner pain during
sex (Maughan, Heyman, & Matthews, 2002; Perz et al., 2014; Sanders, Pedro, Bantum, & Galbraith, 2006). Difficulties relating to sexuality and psychological distress are likely to have greater prevalence in partners of palliative patients, given that the rates of psychological distress in cancer carers are highest when the patient is in the advanced cancer or palliative stage of their illness (Burridge, Barnett, & Clavarino, 2009). For example, one review reported that 30-50% of cancer carers met criteria for psychiatric morbidity (Pitceathly & Maguire, 2003), with female carers reporting higher rates of distress than male carers (Perz, Ussher, Butow, & Wain, 2011). Indeed, partners have also reported that their experience of psychological distress has contributed to interruptions to their sexuality and engagement in sexual practices with the patient (Gilbert et al., 2009; Hawkins et al., 2009). In addition to the concerns reported above, this experience of psychological distress may also relate to the overall loss or diminishment of their sexual or intimate relationship, or to the stress and exhaustion associated with the caring role (Gilbert et al., 2009). Lastly, partners have also reported finding it difficult to negotiate medical equipment, such as facial masks and cannulas, during sex, or when expressing intimacy (Taylor, 2014).

Whilst many patients and partners have reported disruptions to their sexual and intimate relationships post-cancer, in reviewing the literature it was found that a minority of studies have reported that couples were able to renegotiate or improve their sexual and intimate relationship post-cancer. For example, in one study of 156 partners of cancer patients, it was found that 19% of women and 14% of men were able to renegotiate their sexual relationship, by including non-coital sexual and intimate practices such as massage, oral sex, and autoeroticism, hugging and kissing (Hawkins et al., 2009). Couple relationships may also strengthen post-cancer. For
example, some couples have reported better communication post diagnosis (Ussher, Perz, & Gilbert, 2011), as well as greater relationship solidarity after having experienced the opportunity to provide support and care to each other during the cancer journey (Lindau et al., 2011). Looking at the palliative care context, it appears that non-coital sexual practices, and emotional intimacy, may become even more important at this stage, with several studies reporting that couples have re-prioritised these forms of sexual expression, as well as emotional connectedness (Lemieux et al., 2004; Taylor, 2014; Vitrano et al., 2011).

Finally, in the context of palliative care, it has been argued that the sexual and intimate relationship shared by the couple is impacted by the impending death of the patient. For example, it has been suggested that some couples may seek a stronger intimate relationship with their partner, whilst others may desire intimacy, yet begin to disconnect in anticipation of the grief they will experience when the patient dies (Redelman, 2008). However, despite recognition that the intimate relationship between couples is likely to be impacted by the impending death of the person with cancer, to date little research in this area has explored this issue. As such, some researchers (Redelman, 2008; Stausmire, 2004) have called for further exploration on issues such as how couples’ intimate relationships are affected by the impending death of the person with cancer, and what type of intimacy occurs near death and how close to death.

Constructionist approaches to examining sexuality post-cancer.

Whilst much of the cancer and sexuality research has focussed on examining material and intrapsychic changes to sexuality, a smaller proportion of the cancer and sexuality research adopted constructionist approaches to examining post-cancer sexuality. As such, discursive research examined how medical and sociocultural
constructions of sexuality shape patient’s post-cancer gendered and sexual selves, their sexual relationships, and their engagement with the medical system. I will now go on to discuss these issues.

**Changes to gendered identity following cancer.**

Some studies have explored how the socially constructed gendered and sexual identity of individuals with cancer is impacted following cancer. In particular, these studies identified that abject bodily changes often position cancer and palliative patients outside boundaries of normality and gendered identity (Gilbert et al., 2012; Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004), and as a consequence, cancer and palliative patients can report psychological distress, lower emotional health, and sexual dysfunction (DeFrank, Mehta, Stein, & Baker, 2007; Moreira & Canavarro, 2010). Cancer and palliative patients have reported making efforts to conceal these abject bodily changes, for example, through the use of prostheses, wigs, makeup, clothing, diet and exercise (Parton et al., 2015). Yet, concealment cannot always be achieved, with head and neck cancer patients, for example, reporting that they cannot conceal visible facial and neck changes (Callahan, 2005), which can lead to ongoing psychological distress. Advanced cancer patients have also reported that as their illness progressed it became harder to conceal these changes and 'pass' as 'normal' (McClelland, 2015). However, there is also evidence to suggest that some individuals may be able to adjust positively to these bodily changes. For example, for women, this may occur by resisting feminine ideals of beauty, or by re-positioning these changes as bodily signifiers of their ability to face cancer and survive (Gilbert et al., 2012; Parton et al., 2015; Rubin, Chavez, Alderman, & Pusic, 2013).
In relation to male cancer and palliative patients, it was found that the loss of sexual desire and the inability to perform coital sex without medical aids left many heterosexual and non-heterosexual men feeling less confident, and as though they were ‘not a real man’ (Arrington, 2003; Bertero, 2001; Dieperink, Mark, & Mikkelsen, 2015; Fergus, Gray, & Fitch, 2002; Gurevich et al., 2004; Ussher, Perz, & Gilbert, 2015). This occurred because these changes to their sexual functioning violated phallocentric constructions of hegemonic masculinity, where ‘real’ men are positioned as having a biological need for coital sex, which they ‘should’ be able to perform with ease (Hollway, 1984b). However, older men were reportedly less distressed by these changes, as they were able to normalise their loss of sexual functioning by associating these changes as part of the aging process (Gilbert et al., 2013; Ussher, Perz, & Gilbert, 2015).

Changes to the gendered identity of women have also been explored. For example, it has been found that the loss of reproductive organs or the development of infertility can diminish women’s identities of femininity and motherhood (Butler, Banfield, Sveinson, & Allen, 1998; Greil, Slauson-Blevins, & McQuillan, 2010; Juraskova et al., 2003). Visible and non-visible changes to women following cancer can also challenge feminine ideals of beauty. For example, some women have reported finding hair loss to be a distressing experience, because they were not able to be recognised as a woman in public (Gilbert et al., 2012). Scarring, sagging, and other changes to the skin also violate ideals of feminine beauty ideals of flawless, clear skin (Bordo, 2003), and can lead women to feel sexually unattractive (Gilbert et al., 2010b; Parton et al., 2015). Lastly, some women have reported that symptoms of pain, fatigue, and decreased sexual desire have led them to liken their bodies to those of older women’s (Parton et al., 2015). Accordingly, given the dominant cultural
construction that sex is for the young and beautiful (Shildrick, 2005), these women positioned themselves outside of discourses of sexuality.

**Patient experiences of the medicalisation and de-sexualisation of the body.**

A few studies have examined how biomedical constructions of the body, which are often applied to patients’ bodies whilst they receive medical treatment, can lead to desexualisation of the patients’ body; an experience which is incongruent with the patients’ sexual positioning of the body. For example, in one qualitative study which examined how patients and medical clinicians construct sexuality following pelvic radiation, it was found that clinicians often spoke of women’s vaginas in terms of risk for disease-recurrence, as well as how, using non-sexual medical language, dilators could be used to maintain receptivity for coital sex (White, Faithfull, & Allan, 2013). In contrast, female patients reported feelings of distress following this de-sexualisation of their body, and because they were unable to discuss with clinicians how these bodily changes disrupted their sexual relationships, their constructions of femininity, and their concerns about sexual recovery. Similarly, in an ethnographic study, it was found that although men wished to talk about how their prostate cancer treatment had altered their sense of masculinity and changed their intimate relationships, clinicians primarily only spoke about sexual changes in terms of physiological sexual dysfunction (Forbat, White, Marshall-Lucette, & Kelly, 2011).

**Loss of control of the body and sexuality.**

Other studies have examined how patients experience loss of control of the body following cancer and cancer treatments, and how this may impact patients’ sexual selves and couples’ sexual relationships (Manderson, 2005; Rozmovits & Ziebland, 2004; Waskul & van der Riet, 2002). Loss of control of the body is
commonly experienced as distressing for patients, leading them to feel sexually unattractive, embarrassed, ‘uncontained’, and feeling as though they need to ‘manage’ their bodies during sex (Waskul & van der Riet, 2002). For example, individuals who are incontinent (Klaeson, Sandell, & Berterö, 2012), or who have stomas (Manderson, 2005) or catheters (Hawkins et al., 2009) may fear leakage during sex. It has been found that both patients and their partners may experience feelings of disgust in response to these abject bodily changes, and that these continence issues may contribute to a cessation in sex (Taylor, 2014). Partners, in particular, may reposition the patient as ‘asexual’ or ‘childlike’, because the loss of bodily control and the increased dependency that may co-occur is antithetical to adult identity and Western social constructions of adult sexual relationships (Gilbert et al., 2009; Rozmovits & Ziebland, 2004).

It has been documented that the quality of partner support shapes how patients adjust to these continence issues. Specifically, cessation of sex by partners may reinforce and produce feelings of unattractiveness, whilst patients who have partners who continue sexual relations are more likely to feel desirable and affirmed following surgery (Manderson, 2005). For those not in a relationship, it has been found that un-partnered people with cancer report difficulties in disclosing these continence problems to new partners (Manderson, 2005; Rozmovits & Ziebland, 2004; Waskul & van der Riet, 2002).

**Hetero-sex is ‘Real’ Sex: Heteronormativity in the Cancer and Sexuality Literature**

The majority of research studies examining cancer and sexuality drew on a heteronormative biomedical and broader cultural discourse of sexuality which positions hetero-sex as coital sex, that is, vagina/penis intercourse (Hyde, 2007;
White et al., 2013). Accordingly, within this construction of sexuality, the ‘coital imperative’ is privileged as ‘real’ sex, whilst other sexual practices become positioned as secondary or supplementary (McPhillips et al., 2001). Positioning sex within the coital imperative means that the sexual needs of individuals who are in non-heterosexual relationships, or who are un-partnered, are marginalised (Brown & Tracy, 2008; Hordern, 2008; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Indeed, this was reflected in the research literature I reviewed, with many studies, including those looking at the sexual needs of palliative cancer patients, only examining the sexual concerns of heterosexual couples (e.g., Beck, Robinson, & Carlson, 2009; Lemieux et al., 2004; Vitrano et al., 2011), with few studies examining the sexual concerns of un-partnered or non-heterosexual patients and couples (e.g., Hordern & Street, 2007b; Taylor, 2014; Ussher, Perz, & Gilbert, 2014).

The lack of research in this area is problematic, as it may contribute to the invisibility of the needs of non-heterosexual and un-partnered individuals in health care settings, including palliative care settings, as well as implicitly reinforce heteronormative assumptions that are often present within health care settings. Indeed, both groups have reported feeling as though they are less likely to receive support about sexual changes from the health care system, compared to patients who identify as heterosexual, or are in a relationship (Fobair et al., 2002; Ussher, Perz, & Gilbert, 2013). In relation to non-heterosexual individuals with cancer, some have reported experiences where health professionals have assumed that they were in a heterosexual relationship; an experience which may contribute to their perception that health care systems do not provide adequate support for non-heterosexual patients and their partners (Filiault, Drummond, & Smith, 2008). Non-heterosexual patients have also expressed concern that they may experience homophobia if they
disclose their sexual orientation within health care settings (Filiault et al., 2008). Indeed, in one Australian study which interviewed health professionals to identify issues for lesbian, gay, bisexual and transgendered patients who were receiving end-of-life care, the participants reported that they had witnessed a number of discriminatory issues, some of which related to sexuality and recognition of same-sex relationships (Cartwright, Hughes, & Lienert, 2012). These included other health professionals not recognising the chosen identity of transgendered patients, as well as same-sex partners not being included in end-of-life decision planning, which reportedly de-legitimated the relationship of these couples and compounded their experience of grief. In addition, un-partnered people with cancer have also reported feeling largely invisible to health professionals, who reportedly rarely raise issues of sexuality with them (Ussher, Perz, & Gilbert, 2013). Un-partnered people with cancer have also reported that much of the available information on sexuality and intimacy appeared tailored towards people who were in relationships, and so did not adequately address their sexual concerns (Ussher, Perz, & Gilbert, 2013).

Further, little is known about how non-heterosexual and un-partnered individuals with cancer may experience post-cancer sexual changes and renegotiate their sexual practices, given the lack of research in this area. Looking at the few studies which have included un-partnered individuals with cancer, it is evident that they may experience more difficulty with their post-cancer sexuality in some areas, compared to those who are partnered. For example, in a sample of men with testicular cancer, it was found that, despite single and partnered men both reporting sexual desire, single men were found to have greater levels of sexual dysfunction in all other areas, such as erectile dysfunction and sexual satisfaction, than partnered men (Tuinman et al., 2010). Further, in a study of women with breast cancer, it was
found that single women reported greater feelings of sexual unattractiveness and embarrassment compared to partnered women (Fobair et al., 2006). Additional research is needed to explore factors that may explain these differences in experiences of post-cancer sexual changes between these two groups. Un-partnered people with cancer have also reported concerns about finding a new sexual partner. For example, single female cancer survivors have reported concerns about the possibility of being rejected by potential sexual partners, due to perceptions that they will share feelings of “disgust” (Ramirez et al., 2010, p. 617) at the bodily changes they have incurred post-cancer. Un-partnered people with cancer have also reported concerns about revealing their cancer diagnosis to new partners (Gilbert et al., 2013; McClelland et al., 2015; Tindle, Denver, & Lilley, 2009). Given the paucity of research that exists in this area, and also given that the number of un-partnered people in Australia has grown over time (ABS, 2009), it appears particularly important that further research on the sexual concerns and experiences of single people with cancer be considered. Further, to date no research has explored the sexual and intimate concerns of un-partnered cancer patients receiving palliative care, with the existing palliative care, cancer and sexuality research having only included patients who were partnered (e.g. Lemieux et al., 2004; Vitrano et al., 2011). Further research is therefore needed to explore the sexual and intimate concerns of un-partnered cancer patients who are receiving palliative care.

Research is also lacking in relation to how non-heterosexual individuals with cancer, as well as those receiving palliative care, experience post-cancer sexual changes and renegotiation of sexual practices. However, the few research findings in this area have indicated that there are differences between heterosexual and non-heterosexual populations. For instance, lesbian women with cancer, including those
receiving palliative care, have reported fewer concerns with body image compared to heterosexual women (Arena et al., 2007; Ussher et al., 2014), and have reported feeling more comfortable revealing their post-cancer bodies to others (Fobair et al., 2001). There is also evidence to suggest that the post-cancer sexual practices of non-heterosexual women may be less affected than heterosexual women, given that non-heterosexual women are more likely to have a broader sexual repertoire pre-cancer, including non-penetrative practices and intimacy (Boehmer, Potter, & Bowen, 2009; Ussher et al., 2014). Looking at men with cancer, including those receiving palliative care, it has been found that regardless of whether they identify as heterosexual or non-heterosexual, men report that the loss of sexual functioning and performance is their greatest sexual concern post-cancer, as it contributes to a loss of hegemonic masculine identity (Fergus et al., 2002; Gilbert et al., 2013). Despite this, however, some gay men perceive that gay men with prostate cancer may be better able to retain a sense of manhood than heterosexual men following disruptions to sexual performance, as being a sexual minority, they would be able to draw on more diverse and alternative definitions of masculinity that are present within gay and bisexual culture (Asencio, Blank, Descartes, & Crawford, 2009). Further research is needed to explore any potential differences between how heterosexual and non-heterosexual men may reconcile their masculine identities post-cancer.

In sum, the findings of these studies demonstrate the need for un-partnered and non-heterosexual individuals with cancer to be included in future research. Inclusion of these two groups may contribute to their post-cancer sexual concerns having greater visibility and acknowledgement within health care settings – including within palliative care settings - and may also assist in avoiding any
conflation that their sexual needs are the same as patients who identify as heterosexual.

(Un)Healthy and (Dys)Functioning Sexual Bodies: Biomedical Definitions of Sexuality in the Cancer and Sexuality Literature

There are additional limitations that arise when a biomedical approach is taken to understanding sexual issues post-cancer. When a biomedical discourse is adopted, sexuality and the body become defined within binary terms, as either functioning or dys-functioning, normal or abnormal, healthy or unhealthy (Conrad, 2007; Tiefer, 2004). The sexual body is deemed as ‘healthy’, ‘normal’, and ‘functioning’, if the body can perform in accordance with physiological norms of sexual function, and if individuals are willing and desire to engage in coital sex (Tiefer, 1996). The majority of studies which I reviewed adopted biomedical definitions of sexuality and as such, predominantly examined changes to sexual functioning post-cancer, and how coital sex could be restored post-cancer, to the exclusion of discussing non-coital sexual practices (e.g., Audette & Waterman, 2010; Jensen et al., 2004; Ratner, Foran, Schwartz, & Minkin, 2010; Weijmar Schultz & Van de Wiel, 2003). This occurred, despite some of these studies initially commencing their paper by providing a holistic definition of sexuality (e.g., Audette & Waterman, 2010; Muir, 2000). For example, Audette and Waterman (2010), initiated their discussion by introducing a broad and holistic definition of sexuality that comprises of more than sexual functioning:

Sexuality is a complex, multidimensional aspect of human behavior that is represented throughout life and encompasses physical, functional physical, functional and psychological expressions of pleasure, intimacy and
reproduction. The determination of a person as a sexual being is dependent upon the individual’s societal, religious and family traditions. (p. 357).

However, despite these articles initially acknowledging sexuality as inclusive of more than sexual functioning, they then went on to only discuss disruptions to sexual functioning and the restoration of coital sex (Hyde, 2007).

The limitations associated with studies uncritically adopting a biomedical approach to exploring post-cancer sexual changes are as follows. Firstly, there is the potential for patients who are no longer physically able to engage in coital sex following cancer, yet may still desire sex, to be marginalised (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). When studies focus exclusively on examining changes to, and addressing ways in which coital sex can be restored, they do not acknowledge, and implicitly delegitimise, the other ways in which patients may still be able to engage in sexual practices post-cancer. This is potentially quite problematic in a palliative care context, given that previous research has evidenced that palliative care patients report that non-coital forms of sexuality, such as emotional connectedness and non-coital intimate touch, become more important at the end of life (Lemieux et al., 2004; Vitrano et al., 2011). Advanced cancer patients are also more likely to experience disruptions to their sexual functioning than early stage cancer patients (Ananth et al., 2003). Similarly, it has been documented that some couples may cease other forms of intimacy due to concerns that it may lead to coital sex, which has become physiologically impossible for them post-cancer (Gilbert, Ussher, & Perz, 2010b; Rossen et al., 2012). Correspondingly, people with advanced cancer have reported that they want to receive information about non-coital sexual practices, and support to renegotiate their sexual relationship (McClelland et al., 2015).
A second issue which occurs when a biomedical approach is taken to examining post-cancer sexual changes is that the sexual needs and concerns of individuals whose reproductive organs are not affected by cancer and cancer treatments are overlooked. This was evident in the existing pool of literature which has examined cancer and sexuality, where I found that the majority examined sexuality and cancers of the reproductive organs, including prostate, cervical, ovarian, uterine, and vulvar cancers (e.g., Audette & Waterman, 2010; Bertero, 2001; Gilbert et al., 2011; Oskay, Beji, Bal, & Yılmaz, 2011; Ratner et al., 2010) - the site where coital sex can be most obviously disrupted. Further, as a large proportion of the cancer and sexuality literature also examined breast cancer and sexuality (e.g., Gilbert et al., 2010b; Henson, 2002; Sheppard & Ely, 2008) - the breasts being a visible bodily signifier of femininity - there is also evidence of discourses of femininity present within the literature. However, cancer and palliative care patients can experience disruptions to their sexuality, regardless of whether cancer and cancer treatments have directly affected their reproductive organs (Perz, Ussher, & Gilbert, 2013). For example, individuals who have experienced lung, head and neck, lymphoma and colorectal cancers have reported subsequent changes to their sexual functioning, gendered identity, intimate relationships, and engagement in sexual practices (Beckjord, Arora, Bellizzi, Hamilton, & Rowland, 2011; Carolan, Meneses, Shell, & Zhang, 2008; Lindau et al., 2011; Low et al., 2009). Yet, when the predominant focus of the literature is on cancers and cancer treatments that impact coital sex and visible signifiers of gendered identity, this literature contributes to the construction of a fragmented sexual body, rather than acknowledging that sexuality and sexual practices can be a whole body experience (Gilbert et al., 2012).
The final limitation associated with taking a biomedical approach to examining sexuality post-cancer, is that there is a possibility that patients could be pathologised if they lack desire or interest in sex. Women, in particular, may be at particular risk of being pathologised for lacking desire or interest in sex (Drew, 2003). For example, in many of the studies reviewed, sexual desire is measured according to the individual’s willingness to engage in coital sex (Li & Rew, 2010; Tiefer, 2004). This was apparent in these studies as although they used the terms ‘sex’ and ‘sexual activities’, it appeared as though these terms were used synonymously with coital sex. This was evident given the absence of sex being defined as inclusive of sexual acts other than sexual intercourse. It was also evident because the results of these studies solely focussed on how body image and physical changes impacted on cancer patients’ desire for, and satisfaction with, ‘sexual intercourse’, whilst not including the impact of these changes on other sexual acts (e.g. Cavalheiro et al., 2012; Platell, Thompson, & Makin, 2004). However, it is known that for women, sexual desire and satisfaction is not merely contingent on coital sex. It has been found that other factors mediate women’s sexual desire and satisfaction, such as touch, and relational connectedness – factors which were not measured or examined in these studies (Meana, 2010; Thomas, Chang, Dillon, & Hess, 2014). Further to this, it has also been demonstrated that women can still report sexual dissatisfaction and low sexual desire, even when orgasm and physiological arousal is attained (Laan, Everaerd, Van Der Velde, & Geer, 1995; Laan & Janssen, 2007; Tiefer, 2002). These research findings suggest that it is insufficient to measure female sexual desire and satisfaction through measuring an individual’s willingness to engage in coital sex alone, and points to the need for a wider approach to measuring sexual desire to be taken. As such, the present study will ask palliative
care health professionals about other factors, such as relational connectedness, that may impact the sexual desire and satisfaction of the female palliative patients that they work with.

Furthermore, when studies exclusively utilise these biomedical measurements of sexual desire, they also often fail to examine the gender-power dynamics that exist in many heterosexual relationships, and which influence women’s relational experiences and sexual practices, including sexual satisfaction and desire (Hyde, 2007). For example, one study found that women were sexually active one year after treatment, despite the majority reporting continuing problems with loss of sexual desire and interest, as well as a lack of vaginal lubrication (Jensen et al., 2004). Further, another study reported that women who were in relationships or who were married were more likely to return to sexual activity, despite 47% of participants reporting that they had little or no desire to have sex with their partners (Carmack Taylor et al., 2004). Whilst these studies have discussed the role of the patient’s physical symptoms, body image, age and menopausal status, as preclusion to these women’s lack of sexual desire and interest, these studies could also benefit from examining this lack of desire in the context of gender-power relations and the coital imperative in heterosexual relationships. In particular, other research has demonstrated that women may engage in sexual practices not because of a desire for sex, but out of a sense of duty, or to maintain relational harmony (Hayfield & Clarke, 2012a). This is because dominant cultural constructions of gender and sexuality have tended to position women as responsible for male sexual pleasure, with a ‘good woman’, or a ‘good wife’, positioned as one who fulfils their male partners’ sexual needs (Hyde, 2007; Martin, Taft, & Resick, 2007). Indeed, some women may themselves take up the subject position of the ‘good woman’, and thus not view their
engagement in coital sex as problematic, despite a lack of desire for it (Hyde, 2007). Further, women’s engagement in coital sex, whilst undesired, may also stem from the coital imperative, where coital sex is implicitly positioned as an essential component of heterosexual relationships (Potts, 2002). Thus, when studies take such a limited approach to examining sexual desire and satisfaction, they risk endorsing an approach to responding to the sexual concerns of couples, where palliative care health professionals merely restore the sexual functioning of couples, without exploration of how gender-power relations may shape their sexual lives. As such, this thesis will also explore palliative care health professionals’ understandings of how cultural constructions of gender, relationships, and sexuality may shape palliative patients’ and partners’ experiences of sexual consent, and their engagement in sexual practices.

Before this section concludes, it is also worthwhile to consider some possible explanations that may explain why much of the cancer and sexuality literature adopts limited biomedical approaches to examining post-cancer sexuality. Firstly, it is worth acknowledging that the research findings I discussed in this section illustrate the complex interaction of factors which can influence an individual’s experience of sexual pleasure and desire. As such, these findings highlight that it is infeasible for quantitative measures alone to sufficiently examine the multifaceted and complex nature of sexual pleasure and desire. In this vein, I argue that it is important to consider Leonore Tiefer’s assertion that future research needs to employ qualitative approaches, as well as quantitative approaches, to examine how an individual’s experience of sexual pleasure and desire is shaped by cultural meanings and personal history (Tiefer, 2002). Sexual pleasure and desire have been widely acknowledged as
multifaceted constructs (Tiefer, 2012; World Health Organisation, 2004), and as such cannot be measured by physiological or other quantitative approaches alone.

Secondly, when conducting this review, I also observed that a large proportion of the researchers who examined post-cancer sexual functioning using quantitative measures came from the disciplines of medicine, nursing and medical science (e.g., Ananth et al., 2003; Jensen et al., 2004; Rossen et al., 2012). Although sexuality in medicine is acknowledged as a construct shaped by biology and culture, medical education predominantly considers sex in the context of physiological functioning and reproductive capacities (Miller et al., 2013). Arguably then, researchers trained in these disciplines may be less able to consider how sexuality can be examined outside of a quantitative framework.

Finally, it is also important to recognise the omnipresence of heteronormativity and the coital imperative in Western cultures, and that this may influence the bias towards examining heterosex in the academic literature (Tiefer, 1994). For example, in a study examining definitions of sex amongst Western heterosexual male and female individuals, it was found that even though they acknowledged sexual practices outside of coital sex, most participants continued to position penis-vagina coital sex as ‘real’ sex (McPhillips et al., 2001), with participants using the terms sex and sexual intercourse synonymously. Given the taken-for-granted acceptance of the coital imperative as a normative feature of heterosexual relationships in Western culture, this may also facilitate the bias of cancer and sexuality researchers to primarily examine changes to coital sex following cancer, whilst negating other non-coital sexual practices. However, the researchers in McPhillips and others (2001) study also acknowledged that many participants were able to imagine, or even negotiate sex without the involvement of the coital
imperative. It was therefore argued that challenges to the notion that heterosex equals the coital imperative already exist, and that by introducing the idea that intercourse is a choice, rather than an inevitability of heterosexual sexual relationships, “we may undermine the imperativeness of the coital imperative” (McPhillips et al., 2001, p. 239). In this vein, I suggest that greater acknowledgement and visibility of other forms of sexual practices in the cancer and sexuality research may offer patients, partners, and health professionals opportunity to conceptualise multiple discursive possibilities for heterosex.

**How is Sexuality Affected Post-cancer, and What are the Barriers to Discussing Sexuality? The Views of Health Professionals**

Recent research has evidenced that health professionals appear to be increasingly recognising that addressing post-cancer sexual and intimate changes is an important issue. For example, research has shown that many health professionals have positioned discussing sexuality as an area of need and as a responsibility of their professional role (Haboubi & Lincoln, 2003; Lindau et al., 2011). There is also evidence to suggest that they recognise that sexuality and intimacy is an important component of patient quality of life (Tan, Waldman, & Bostick, 2002; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

However, few studies have examined whether health professionals who work in oncology are aware of how sexuality may be impacted post-cancer; with the majority of the literature in this area having examined barriers to health professional communication. Nonetheless, these studies which have examined health professional recognition of post-cancer sexual changes have indicated that health professionals do have an awareness of how sexuality can be impacted post-cancer. Specifically, earlier studies in this area examined whether medically-trained health professionals
(doctors and nurses) were aware of how ovarian cancer (Stead, Brown, Fallowfield, & Selby, 2003) and breast cancer (Lavin & Hyde, 2006) impacted the sexuality of women, and found that they were aware of how cancer treatments can impact the body image of women. For example, health professionals were aware that cancer treatments may cause bodily changes such as vomiting, hot flushes, and scarring which can leave women feeling sexually unattractive. Health professionals in these two studies also recognised that women may have concerns about how their fertility is affected post-cancer, and that the sexual functioning of patients may be disrupted.

Later research has broadened this area of research by examining how health professionals may recognise the sexual needs of patients with all types of cancers (Hordern & Street, 2007a; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013), and not only cancers of the sexual organs. One of these studies found that health professionals, including both medically-trained (doctors, nurses) and non-medically trained (psychologists, social workers) health professional groups, were aware of how relationships may be disrupted post-cancer, in addition to recognising changes to body image and sexual functioning (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). For example, health professionals in this study acknowledged that: couples may be concerned about engaging in coital sex due to pain or discomfort; that relationships and intimacy may be re-prioritised at the end-of-life; or that conversely, some couples may end their relationship following a diagnosis of cancer. They also recognised that cancer and the associated bodily changes could impact the feminine and masculine identities of people with cancer. In addition to examining health professionals’ awareness of sexual changes, the ways in which health professionals may respond to these sexual concerns was also explored in this study. For example, a few health professionals talked about giving couples permission to practice non-
coital forms of intimacy, such as touch, when coital sex was no longer possible. In sum, these few studies evidence that health professionals working in oncology have some awareness of the post-cancer sexual changes that patients may experience, and that some health professionals may be able to respond to the sexual concerns of patients and their partners.

However, with the exception of Ussher et al.’s study, the above studies have only explored whether health professionals are aware of the sexual concerns of patients with early stage cancer. This means that little consideration has been given to health professionals’ recognition of sexual concerns within palliative settings, where patients’ and couples’ sexual and intimate needs may be more complex, given the interaction with advanced cancer and anticipation of death (Ananth et al., 2003; Hordern & Currow, 2003). Furthermore, the majority of this literature has not examined how health professionals may respond to these issues of sexuality and intimacy, in incidences where health professionals have reported that they do respond. Rather, the focus has been on examining barriers to discussing sexuality. Examining how health professionals may respond to the sexual needs of patients and couples is an area in need of study, as it will assist in illuminating how health professionals may be able to negotiate and overcome personal and structural barriers to raising sexuality. Finally, no research to date has included bereavement counsellors, who work with the bereaved partners of individuals with cancer. As there is no existing research which has examined how bereaved partners may experience “connecting, disconnecting and re-connecting” (Taylor, 2014, p. 445) in their coupled relationship at the end-of-life, involving bereavement counsellors may assist in revealing the issues that partners may experience regarding this, and how
bereavement counsellors may respond to these issues. The present study will seek to address these gaps in the literature.

Along with this evidence that health professionals have an understanding of the post-cancer sexual changes that may be experienced, it has also been found that the majority of health professionals position themselves as both responsible for giving patients opportunity to discuss their sexual concerns with them, as well as for providing information on sexual changes and treatment (Hautamäki et al., 2007; Jefford et al., 2008; Magnan et al., 2005). However, research has consistently shown that most do not raise or discuss issues of sexuality, unless it is raised by patients or partners themselves (Hordern & Street, 2007a). For example, in a sample of 214 health professionals, approximately one third of which worked in a cancer ward, it was found that 59% of the cancer ward health professionals discussed sexuality with less than 10% of their patients. Further, 92% of the entire health professional sample reported that they did not give written material on sexuality unless it was asked of them (Hautamäki et al., 2007). Likewise, similar findings were observed in another study, where the majority of sampled nurses reported that they never discussed issues of sexual desire, fertility, early menopause risk, contraception, and body image with cancer patients. The key reason given by the sample nurses for their lack of discussions on sexuality was that their patients never reported any sexual concerns to them (Algier & Kav, 2008). These findings demonstrate that having an awareness of post-cancer sexual changes, and agreeing that it is an important issue to address, does not always translate into health professionals attending to these issues in practice. Further, the finding that health professionals do not discuss sexuality unless it is first raised by patients is also concerning, given that most patients have reported not raising sexuality due to feelings of embarrassment, or feeling that health
professionals will consider it inappropriate if patients raise the issue with them (Hawkins et al., 2009; Hordern & Street, 2007b). The majority of patients have also reported that they want the opportunity to discuss sexual concerns with health professionals, and that they want the onus to be on health professionals to raise sexuality with them (Lemieux et al., 2004). There does appear to be, then, a mismatch between the wishes of many patients, and the practices of health professionals, in relation to sexual communication.

Consequently, this has led the majority of the existing research literature to examine barriers to health professional communication in this area. In this vein, the research has consistently identified a number of structural and personal barriers that inhibit communication about sexuality and intimacy in the area of cancer. These structural barriers include: a lack of time and privacy in clinical settings (Carr, 2007; Wiggins et al., 2007); and a perceived lack of knowledge or education, which often leads to subsequent feelings of incompetence in their ability to address sexuality (Hautamäki et al., 2007; Magnan et al., 2005; Matocha & Waterhouse, 1993; Stead et al., 2003). Personal barriers include role ambiguity and diffusion of responsibility, which may include positioning other health professional groups as being the most appropriate group to have the responsibility of addressing sexuality, or assuming that other health professional groups would have already raised sexuality with patients (Jenkins, Fallowfield, & Poole, 2001; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). There is also evidence that health professionals have positioned sexuality as a ‘nonmedical’ issue, and thus felt that it inappropriate to discuss ‘nonmedical’ aspects of patient’s lives (Hordern & Street, 2007b; Lindau et al., 2011). Health professionals have also reported avoiding discussions of sexuality due to feeling as though they cannot be authentic and provide a person-to-person approach (de Vocht
et al., 2011); and perceived feelings of vulnerability and embarrassment if sexuality was raised, given its social construction as a ‘taboo’ topic (Hordern & Street, 2007c; Meerabeau, 1999; Stead et al., 2003). Lastly, it has been argued that palliative care health care professionals may be vicariously impacted by the grief and fear inherent in their patients’ stories, as patients or couples confront the impending reality of the patient’s death, and thus avoid discussions of sexuality and intimacy (Gilley, 1988; Redelman, 2008) – though no research has yet explored this supposition empirically.

Apart from the work of Hordern and Street (2007b) and Ussher et al. (2013), no research has examined how sociocultural constructions of illness, dying, sexuality and age shape how health professionals communicate about sexuality, including what information they might provide, and which patients or partners might be positioned as having post-cancer sexual concerns. Rather, much of the existing literature, and the sexual communication models, such as PLISSIT (Annon, 1981), which are aimed at enhancing health professional communication about sexuality, tacitly assume that if health professionals receive knowledge that sexuality is important, and receive guidelines on how to respond to these issues, that they will simply go ahead and do so (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). However, there is evidence that structural and personal barriers do not completely account for why health professionals do not raise sexuality with people with cancer and their partners, but rather, that it is an interrelation of socio-cultural, structural and personal barriers (Hordern & Street, 2007b; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Further, another assumption underlying these sexual communication models is that the strategies and guidelines they provide will be effective in all contexts. Yet the reality of clinical practice is that health professionals must negotiate
communication on a case-by-case basis, as it is shaped by the inter-relation of these barriers (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

**Sociocultural barriers to acknowledging and responding to sexuality and intimacy in oncology palliative contexts.**

Health professionals can be impacted by taboos around sexuality, illness, dying and aging which may lead them to position some people with cancer and their partners as not needing to know about issues of sexuality and intimacy. When health professionals position patients and couples in this way, the sexual and intimate needs of these individuals are likely to be unrecognised and consequently not addressed.

The ageist discourse, which positions older people as non-sexual beings (Bevan & Thompson, 2003; McAuliffe, Bauer, & Nay, 2007), who, as they increase in age, are assumed to express less interest in sexual and intimate issues and in maintaining sexual activity (Hordern & Currow, 2003), has been found to inhibit health professionals from acknowledging that older patients may have sexual concerns. For example, Hordern and Street (2007c) found that health professionals in their study felt that older people would not regard sexuality as an important issue that they wished to be addressed. Similarly, another study, conducted in a non-palliative setting, found that general practitioners and nurses positioned that older people would be offended if they raised sexual issues (Gott, Galena, et al., 2004). However, although health professionals may have positioned older people as not wanting to discuss sexuality because they would regard it as a taboo or unimportant, it is evident that this assumption contradicts reports by older people, including those with cancer and in palliative care, who report wanting the opportunity to discuss sexual changes, and how sexuality can continue to have an ongoing role in their life (Ananth et al., 2003; Bradway & Beard, 2015; DeLamater & Sill, 2005; Gott & Hinchliff, 2003;
Neglecting to address sexuality with older people with cancer is also a significant issue given that the majority of individuals receiving palliative care are in the older age groups (AIHW, 2012). It is, therefore, important to examine how this discourse of age and sexuality may inhibit sexual communication in palliative settings.

It has also been found that health professionals may draw on heterocentric biomedical constructions of sexuality, which result in inhibiting health professional communication about sexuality in the context of cancer. For example, a few studies found that most health professionals, from both cancer and palliative settings, adopted medicalised constructions of sexuality, and subsequently only discussed the medicalised aspects of sexuality, such as sexual functioning, fertility, menopause and contraception (de Vocht et al., 2011; Forbat et al., 2011; Hordern & Street, 2007b; White et al., 2013). This meant that ‘non-medical’ changes to sexuality were ignored by health professionals, contrary to the wishes of the people with cancer who also participated in these studies. However, a more recent study, which I discussed in more detail earlier, found that the majority of health professionals adopted a wider approach to understanding post-cancer sexual changes, describing relational and psychological sexual changes, as well as physical changes (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). One explanation that could explain this discrepancy in findings is that it may reflect the increased attention that cancer and sexuality has been given in the research literature since Hordern and Street’s paper was published in 2007 (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Accordingly, further research is needed to explore whether health professionals’ constructions of sexuality have since changed.
However, although health professionals in Ussher et al.’s study acknowledged non-medical changes to sexuality, this study confirmed that health professionals may still adopt a heterocentric construction of sexuality, where ‘real’ sex is positioned as coital sex. Confirming previous research (Brown & Tracy, 2008; Filiault et al., 2008; Ussher, Perz, & Gilbert, 2013), this resulted in the sexual needs of some patients and couples being marginalised. Specifically, those who had non-reproductive cancers which did not directly affect the sexual organs, who were un-partnered, or who were in non-heterosexual relationships were likely to have their sexual concerns unacknowledged. This heterocentric construction of sexuality also meant that the majority of health professionals adopted a construction of sex as performance, which meant that consideration was not given to other ways patients could continue to express their sexuality when coital sex was physically no longer an option. Given that palliative patients are more likely to experience greater disruptions to their sexual functioning, and may position intimacy as having greater importance at the palliative stage of their illness (Lemieux et al., 2004; Vitrano et al., 2011), it is therefore particularly important to look at how palliative health professionals may construct the sexuality of palliative patients, and how, if recognised, they may respond to their sexual concerns. For example, it may be that palliative care health professionals are more likely to recognise the importance of intimacy and non-coital expressions of sexuality, in accordance with the reports of many palliative patients. On the other hand, however, it would clearly be problematic if health professionals adopted heterocentric constructions of sexuality in the context of palliative care. Thus, this study will examine how health professionals construct and respond to sexuality in the context of palliative care.
Another issue to consider is that although structural and personal constraints to raising sexuality do exist across many clinical settings, health professionals may also draw on sociocultural constructions of the ‘good’ health professional to deflect their avoidance of raising sexuality, through positioning their lack of sexual communication as simply a result of these structural and personal constraints. For example, Ussher et al (2013) looked at the discursive function of adopting a subject position of not having enough knowledge or experience in addressing sexuality (a personal barrier), arguing that adopting this subject position allows health professionals to excuse themselves from discussing sexuality, because ‘good’ health professionals are expected to operate within their area of expertise and knowledge. Similarly, by drawing attention to the time and privacy constraints of many clinical settings, health professionals may also be positioning themselves as operating in the best interests of patients, by avoiding discussions of a ‘taboo’ topic in these situations where discussing sex is not ideal. These findings demonstrate that it is important to examine how sociocultural constructions of the health professional role may interact with personal and structural constraints in health settings.

Another area of research which has not been examined in this area is how the discursive construction of health settings may shape health professional communication about sexuality. Poststructuralism, and in particular, Foucault’s (1976) work on discourse, has allowed for geographical space to be reconceptualised as a socially constructed and layered phenomenon, constituted through discourse (Kearns & Moon, 2002; Massey, 1999). As such, this enables a conceptual framework for understanding how particular spaces, such as institutional ‘public’ health care settings (hospitals and hospices), enable or constrain particular practices (Malpas, 2003), such as health professional-patient sexual communication and
patient expressions of sexuality and intimacy. For example, the biomedical discourse has been identified as the dominant discourse within hospital settings, and so correspondingly, care in institutional settings is centralised around providing care for the physical body (Gilmour, 2006). As such, the present structural barriers in hospital settings arguably relate to the influence of the biomedical discourse. That is to say, clinical consultations and patient rooms (often shared) are organised around providing ‘medical’ treatments and efficient care of the physical body (Foucault, 1975). Therefore, the hegemony of the biomedical discourse may mean that in clinical settings, less attention is given by health professionals to care of the psychosocial aspects of patients, including the ‘non-medical’ aspects of sexuality. The structural constraints of these settings, particularly a lack of privacy, may also serve to limit patient expression of sexuality and intimacy in hospitals (Lemieux et al., 2004).

Further, it appears that examining the discursive constructions of space is a particularly important and needed area of research in the context of palliative care and sexuality, given that the settings in which palliative care is provided are more diverse than in oncology, and as such, the structural and discursive barriers across these settings will likely differ. For example, palliative care can be provided in hospices, which often have more private rooms than hospital settings, as well as in the home, where patients ostensibly have more control over the amount of privacy they have. Additionally, palliative care hospices appear to adopt the aims of the palliative care discourse, where pain and suffering is considered as a multidimensional construct, encompassing physical, psychosocial and spiritual aspects (Exley & Allen, 2007; Mino & Lert, 2005). This may mean that the space of hospices may be more conducive to health professionals acknowledging and
responding to issues of sexuality, as well as providing greater opportunity for patient expressions of intimacy and sexuality, than hospital settings. Therefore this study will examine whether, and how, the different settings where palliative care is provided shape health professional communication and practices about sexuality.

Equally, no research to date has compared whether health professionals working in predominantly palliative settings may construct and respond to sexual issues differently from those working with mostly non-palliative patients. Rather, much of the existing literature has included health professionals working with predominantly non-palliative patients. This is an oversight, as there may be differences in how these two health professional groups communicate about sexuality. For example, two studies found, after asking their sample of health professionals who worked in a non-palliative setting whether they thought that their patients were ‘too ill’ to be interested in sex, that the majority disagreed with this statement (Magnan et al., 2005; Saunamaki et al., 2010). Yet, it has been suggested that health professionals working in palliative settings may be more likely to position patients as ‘too ill’ for sex, given that patients in palliative care are usually physically debilitated to a greater degree as a result of their advanced cancer stage (Ananth et al., 2003; Matzo & Hijjazi, 2009). If this is the case, then some palliative patients may be positioned as not needing to receive information about post-cancer sexual changes, and their concerns may not be addressed. The present study will seek to explore this issue.

Finally, health professionals working in non-palliative settings have reported the assumption that oncology patients would not position sexuality as a priority, but rather, that they would want their health professional team to focus on assisting them to survive their cancer (Hordern & Street, 2007a; Lindau et al., 2011; Stead et al.,
2003). However, this assumption may function to excuse oncology health professionals from addressing sexuality, by enabling professionals to construct themselves as operating in accordance with the wishes of patients; albeit having not ‘checked out’ with patients whether such an assumption is correct. Indeed, there does appear to be a mismatch in expectations between health professionals and patients on this issue, with oncology patients consistently reporting that they wish health professionals to give them the opportunity to talk about their sexual changes, and not merely focus on survival (Hordern & Street, 2007a). Moreover, this assumption might also implicitly construct palliative care as the ‘right context’ to talk about sexuality, given that in this setting the majority of patients have a life-limiting illness, and so their care is centred on enhancing quality of life, and not survival. Therefore, the above demonstrates that there is a need to examine how health professionals construct sexual communication in palliative settings, in order to explore how sociocultural constructions around dying, illness and sexuality may function to facilitate or inhibit sexual communication within these settings.

**Conclusion**

In this chapter it was reported that cancer patients often experience physical body changes, psychological distress and changes to body image which can disrupt their sexual functioning, emotional wellbeing and engagement in sexual practices. Palliative care patients were found to experience greater adverse changes to their sexual functioning and practices than those with early stage cancer; however it was found that there is a limited amount of research which has examined the sexuality of palliative patients and partners. It was also found that the partners of cancer patients can experience an increase in psychological distress and changes to their sexual functioning. Many couple relationships were also found to be adversely impacted
post-cancer, though it was found that a smaller proportion of couples experience a strengthening of their relationships, or are able to successfully renegotiate their sexual practices.

I argued that it is important for research in this area to consider how discursive factors interact with material and intrapsychic changes, and shape the post-cancer sexual experiences of patients and partners. Without consideration of sociocultural and medical constructions of sexuality and heterosexuality, the research literature may continue to implicitly endorse constructions of sexuality as coital sex, and accordingly exclude groups of patients and partners who cannot engage in, or do not desire, coital sex. This research will also be limited in its capacity to acknowledge and challenge gender-power issues that are present within some heterosexual relationships. Finally, future research in the area of cancer and sexuality would benefit from acknowledgement of how the post-cancer gendered identities of patients is shaped by discourses of hegemonic masculinity and idealised constructions of feminine beauty and motherhood. An acknowledgement of these issues would also contribute to positively shaping the knowledge of oncology and palliative care health professionals in regards to the sexual concerns and needs of palliative patients. It may also facilitate health professionals’ consideration of how sociocultural constructions shape the post-cancer sexual subjectivities of their patients and partners.

In this vein, I also established that sociocultural and medical constructions of sexuality, age, dying and illness, along with personal and structural factors, may also work to facilitate or limit the capacity of health professionals to recognise and respond to the sexual needs of palliative patients and partners, despite the fact that much of the existing research has not considered these discursive factors. I therefore
argue that a post-structuralist theoretical perspective can facilitate examination of how discursive, material and intrapsychic factors shape the subjectivities and communication practices of oncology health professionals who work in palliative care, and how they may negotiate these factors in their practice.
Chapter Three: Methodological Framework

This chapter outlines the research design, recruitment procedure, and the sample of the health professionals who were interviewed. I will then outline the interview procedure, which will include an overview of the interview schedule and the context in which the interviews took place. Lastly, I will explicate how the interview accounts were analysed; including details of transcription, coding, and the method of thematic discursive analysis.

Research Aims and Design

The aim of this study was to explore how health professionals communicate about issues of sexuality and intimacy with people with cancer who are receiving palliative care and their partners. The following questions were used to guide the study: How do health care professionals construct sexuality and intimacy in the context of palliative care and cancer? What are health care professionals’ experiences of communicating about issues of sexuality and intimacy in the context of palliative cancer care? How do discursive constructions of sexuality shape the communication practices of health care professionals in the context of palliative cancer care? A qualitative design was employed, with semi-structured interviews conducted with thirty palliative cancer care health professionals. Participants were purposively sampled to recruit those who had experience working in palliative care across four health professional groups; specifically, physicians, nurses, social workers and psychologists or counsellors. Further, participants were purposively sampled across varying age and gender, so that their experiences of communicating about sexuality could be examined across these factors. Audio-recorded semi-structured interviews were conducted face-to-face or over the telephone with thirty health care professionals, and all were transcribed verbatim. A thematic discourse analysis was
conducted, informed by a poststructuralist approach to discourse (Foucault, 1975, 1976), and a material-discursive-intrapsychic approach (Ussher, 2000, 2004), and situated within a critical realist perspective (Bhaskar, 2011). This approach enabled examination of how material and intrapsychic factors, as well as socio-cultural and medical discourses, shape health professionals’ constructions of sexuality and sexual communication practices in the context of cancer and palliative care (Burr, 2003; Sims-Schouten et al., 2007).

**Recruitment Procedure**

This study was approved by the University of Western Sydney’s Human Research Ethics Committee (see Appendix 1). Most of the participants who took part in this study responded to an invitation that was circulated through professional palliative care networks. More specifically, after receiving ethics approval from the University of Western Sydney, a flyer (see Appendix 2) was emailed out to members of the following organisations: Palliative Care Australia, Palliative Care New South Wales, Palliative Care Queensland, The Australian and New Zealand Society of Palliative Medicine, and the Sydney-based Psycho-Oncology Cooperative Group (PoCoG). Snowballing methods also facilitated the recruitment of participants, as some of the participants in my study reported that their colleagues had forwarded them the email which included the invitation to participate in the study. Finally, some of the participants involved in this research had responded to flyers for the study that had been advertised at a New South Wales-based metropolitan hospital and hospice, following site-specific ethics approval from the relevant Health authority.

Before commencing the interviews, health professionals indicated that they had either past or current experience working in palliative care and cancer, which fulfilled the criteria for participating in this study. Health professionals were
purposively sampled from four of the following health professional groups: physicians, nurses, social workers, and counsellors or psychologists. These health professional groups were chosen because palliative cancer patients have reported that these are the health professional groups that they would prefer to discuss sexuality and intimacy with (Lemieux et al., 2004; Vitrano et al., 2011). However, patients or their partners may raise these issues with any health professional, simply because they have established trust or rapport with that health professional (de Vocht et al., 2011), or because the health professional was there at the ‘right’ time. Another reason why I selected these four health professional groups was to allow for examination of any potential differences in how health professionals communicated about sexuality across either medical or allied health professional groups. For example, previous research found that medically-trained health professionals - in particular physicians - were likely to construct and respond to issues of sexuality in a medicalised way, through addressing how cancer and cancer treatments may impact on fertility and sexual functioning, whilst overlooking other psychosocial sexual and intimate changes (Hordern & Street, 2007c).

Finally, whilst a sampling framework was not used, efforts were made to recruit health professionals across different genders and age, to examine any possible differences in communication across these factors. For example, two studies reported that health care professionals found it challenging to discuss sexuality with patients who were of a similar age to their own parents (Hordern & Street, 2007c; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013), which indicates that the age of health care professionals may shape their communication practices around issues of sexuality. In this vein, although I did not set out to have a specific number of participants from different age groups, I ceased recruiting when I had gathered participants from a
range of ages. Further, whilst I was fortunate that both men and women agreed to participate in the study, I was not able to reach relatively equal numbers of men and women in the study. Rather, the gender ratio of participants in my study is reflective of the distribution of males and females working in these four health professional groups at present. Specifically, in Australia, nurses, social workers, and counsellors who work in health care settings are more likely to be female (AIHW, 2013a, 2013b), whilst the ratio of male and female palliative care physicians is more evenly split (AIHW, 2013c). Similarly, most of the nurses, social workers and counsellors/psychologists who participated in the present study were female, although contrary to the average gender distribution of the palliative care workforce, only one of the four physicians who volunteered to participate in the study was male.

After making contact with me and indicating a willingness to participate in the study, the potential participants were sent a copy of the Information Sheet and Consent Form (see Appendix 3) to view, and were given a broad overview of the topics that would be covered during the interview. All participants were informed that their participation was voluntary, and that they could withdraw from the study at any time, and without giving any reason. Initially, thirty two health professionals expressed interest in participating in an interview, and of this sample, thirty health professionals proceeded to provide their consent to participate in an interview. In relation to the two participants who initially expressed interest, but did not proceed with involvement in my study: one participant, a physician, withdrew from the study shortly after making contact with me, citing that time constraints precluded him from taking part in an interview. The other participant who expressed participating in an interview was an occupational therapist, and thus did not meet the criteria for participating in the study. A few of the participants advised that they were willing to
take part in either an individual or a focus group interview. However, no focus groups were arranged because the participants who were willing to take part in a focus group either lived in different regions of Australia (including in different states), or had conflicting availabilities.

Purposive sampling ceased when theoretical saturation had occurred, where the addition of new data did not create any new theoretical insight (Charmaz, 2006; Minichiello, Aroni, Timewell, & Alexander, 1995). Upon completion of the interviews, all participants and people to whom they refer were assigned pseudonyms, in order to ensure anonymity.

**Participants**

Thirty health care professionals participated in semi-structured interviews - 25 women and 5 men; comprising 4 physicians, 10 nurses, 8 social workers, and 8 counsellors or psychologists, with the latter group including 3 bereavement counsellors who predominantly worked with bereaved carers. The health professionals in this study were aged between 31 and 64, with an average age of 50. The health professionals’ reported length of experience in working with palliative care cancer patients or their partners varied between 9 months and 27 years, with an average of 12 years. At the time of the interview, all of the health professionals were currently practicing in Australia, except for one health professional, who was working in New Zealand. Ten health professionals worked in hospital or hospice settings; fourteen worked in community settings, in either private or hospital-funded therapeutic practices, or in the homes of palliative care patients; and six health professionals worked across both hospital and community settings.
Pen portraits.
The following pen portraits detail the individual demographic characteristics of each participant, including their age, their profession, and whether they work in a hospital, hospice or community setting.

Palliative care physicians.
Ken was 55 years old, and worked as a hospital-based palliative care specialist, in a metropolitan area within Australia.

Sabrina was 39 years old, and worked as a hospital-based palliative care specialist, in a metropolitan area within Australia.

Jennifer was 39 years old, and worked as a hospital-based palliative care physician, in a metropolitan area within Australia. Prior to her role as a palliative care specialist, she had previous work experience in oncology and general practice, where she also worked with palliative care and cancer patients.

Julia was 51 years old, and worked as a hospital-based palliative care specialist, in a metropolitan area within Australia. She had previously worked in oncology.

Nurses.
Brian was 53 years old, and practiced as a palliative care nurse both in the hospital and in the community. He identified that the area of Australia that he worked in was rural.

Heather was 53 years old, and practiced as a community-based palliative care nurse, in a regional area of Australia. She had also worked in aged care.

Fiona was 49 years old, and practiced as a community-based palliative care nurse, in a rural area of Australia.
Margaret was 45 years old, and practiced as a community-based palliative care nurse, in a metropolitan area of Australia.

Jean was 58 years old, and practiced as a community-based nurse coordinator in the area of gynaecological oncology, and was also involved in a state-based palliative network. She identified that the area of Australia she worked in was metropolitan.

Karen was 57 years old, and was a clinical nurse manager of a community-based palliative care unit. She had previously worked in aged care.

Ian was aged 49, and was a clinical nurse consultant, working in the area of palliative care. He worked in metropolitan hospital within Australia.

Kelly was aged 44, and worked as a community-based palliative care nurse. She worked in a metropolitan area within Australia.

Beth was aged 48, and worked as a community-based palliative care nurse, within a metropolitan area of Australia. She had previous experience working in oncology.

Helen was aged 44, and worked as a community-based palliative care nurse within a metropolitan area of Australia. She had 13 previous experience working in aged care.

**Social workers.**

Heidi was 56 years old, and worked as a hospital-based social worker within a metropolitan area. She had previous experience working in gynaecological oncology.

Sarah was 31 years old, and worked as a hospital-based social worker within a metropolitan area. She had previous experience working in aged care rehabilitation.
Pamela was 59 years old, and was a community-based social worker who worked in a rural area.

Dianne was 52 years old, and was a community-based social worker who worked in a metropolitan area.

Janine was 59 years old. She practiced as a social worker within hospital and community settings, in a metropolitan area.

Maureen was 59 years, and was a community-based social worker in a metropolitan area.

Veronica was 58 years old, and was a hospital-based social worker in a metropolitan area. She had previously worked in nursing homes.

Carla was 52 years old, and was a hospital-based social worker in a metropolitan area.

**Psychologists and counsellors.**

Matthew was 33 years old, and worked as a clinical psychologist in the oncology department of a hospital, in a metropolitan area. He worked with patients and partners who were either in the hospital, or in the community.

Kay was 55 years old, and worked as a counsellor at a palliative care unit in a metropolitan area. She worked with patients and partners who were either in the hospital, or in the community.

Jill was 49 years old. She worked as a counsellor in the community, and primarily worked with cancer and palliative care patients in this role.

Judy was 64 years old, and worked as a bereavement counsellor, in a service that received referrals from the adjoining palliative care hospice. Her work included counselling bereaved partners from the community, and she worked in a metropolitan area. Previously she had worked as a nurse, and during this time had
worked with palliative care and cancer patients. During the interview, she talked about her experiences of responding to issues of sexuality in a cancer and palliative care context that she had encountered as both a nurse and as a bereavement counsellor.

David was 50 years old, and worked as a bereavement counsellor, in a service that received referrals from the adjoining palliative care hospice. His work included counselling bereaved partners from the community. He was based in a metropolitan area.

Andrea was 41 years old, and worked as a bereavement counsellor, in a service that received referrals from the adjoining palliative care hospice. Her work included counselling bereaved partners from the community. She worked in a metropolitan area. She had previously worked as a hospital-based nurse. Like Judy, during her interview, she talked about her experiences of responding to issues of sexuality in a cancer and palliative care context that she had encountered as both a nurse and as a bereavement counsellor.

Madeline was 37 years old, and a clinical psychologist working in the oncology department of a hospital, in a metropolitan area. She worked with patients who were receiving hospital-based care, and their partners.

Linda was 47 years old, and a psychologist who worked both in private practice, and in a community-based palliative care hospice. She worked in a metropolitan area.

**Interview Procedure**

Participants were given the option of completing the interview either face-to-face, or over the phone. Due to geographical restrictions, or due to reasons of convenience to the participant, twenty participants chose to have interviews
conducted over the phone, whilst ten participants opted to have the interview conducted face-to-face. The interviews that were conducted face-to-face took place, at their request, at the participant’s place of work in a quiet and private room. The interviews lasted between 30 minutes and an hour and 17 minutes, with most interviews lasting for 55 minutes. The interviews were audio-recorded with the consent of participants, and later transcribed verbatim.

The semi-structured nature of the interview meant that the discussion was comprised largely of open-ended questions that were intended to elicit the participant’s sharing of their experiences about whether or how they communicate with patients and partners about sexuality and intimacy (Kvale, 2009). This format also provided greater flexibility in allowing me to pursue and explore other issues that participants raised during the course of the interview that may not have been covered by the interview schedule (Minichiello et al., 1995). Interview prompts were also used to open up descriptions of participant experiences (Kvale, 2009).

**Preparing and conducting the interviews.**

Before the interview commenced, I assured each participant that they only needed to disclose information that they felt comfortable sharing, and that they could stop the interview at any time. I also informed participants that they could withdraw from the study at any time and without giving any reason (see Appendix 4). The interviews were initiated by asking health professionals how they might define sexuality and intimacy. I asked this question and intentionally left the terms ‘sexuality’ and ‘intimacy’ undefined so that participants had an opportunity to consider and describe their own understandings of sexuality and intimacy, rather than have these definitions imposed by me. Further, although intimacy has been considered as a component of sexuality by the World Health Organisation (2004), I
intentionally asked about sexuality and intimacy separately, in case participants thought that I was only interested in hearing about how they communicated about sexual activities, such as coital sex. Although intimacy can be a part of sexual practices, intimacy, as I defined in my introductory chapter, can also be expressed through non-sexual touch, and through the emotional connection shared between partners (Lemieux et al., 2004; Taylor, 2014). As I had hoped this first question would facilitate, participants gave broad descriptions of sexuality and intimacy in response to this question. For example, participant responses to how they defined sexuality included, “sexuality is central to a person’s identity”, “…their presentation of their gender”, “who I’m attracted to”, “expressing yourself in a sexual way”, “body image”, “sense of self”, and “sexual functioning”. Participant responses to how they defined intimacy included, “intimacy is about connection between two people”, “emotional connection”, “showing vulnerabilities to one another”, and “intimacy can be part of a sexual experience – or it might not be”.

Following this initial question, I then asked participants how they saw sexuality and intimacy in the context of cancer and palliative care. This question, as I intended, allowed participants to consider how sexuality and intimacy may be impacted by cancer and a life-limiting condition, and to consider what challenges patients or partners may face in regards to their sexuality. Following this, I asked participants whether patients or partners had ever raised sexual or intimate issues with them. I then asked participants how they felt about talking about changes to sexuality and intimacy, with prompts used to explore any difficulties they may have experienced, and any topics they thought were important to raise or address with patients and their partners. If participants spoke about finding it now easier to talk about sexuality than they had earlier in their career, I asked prompts to elicit
description about what factors had facilitated this change. I also asked participants whether they had any strategies that they used to raise or discuss sexuality and intimacy. Participants were also asked whose role they thought it was to raise and discuss sexuality and intimacy. Lastly, I asked participants about any training or resources they had received in the area of sexuality and intimacy, and what other training or resources they may like access to. The interview concluded by asking participants whether there was anything else that they wished to talk about, that may not have been already been covered by the interview (Minichiello et al., 1995).

The first three interviews were transcribed, and a preliminary examination was conducted to see if the responses were addressing the research questions, and whether further questions could be added to explore previously unconsidered issues. I found that the participants’ responses were answering the research questions; however some prompts were added to facilitate description of additional issues that were emerging. For example, some participants spoke about their encounters with sexual violence in palliative care, and so an additional question that addressed sexual violence in palliative care was added to the interview schedule.

**Reflections on doing face-to-face and phone interviews.**

As noted above, I conducted both face-to-face and phone interviews, and found that there were advantages to both methods of communication. I found that the method of face-to-face communication helped facilitate the interview interaction, as the participant’s eye contact, facial expressions, and body language could be observed (Miller, 1995; Sturges & Hanrahan, 2004). These visual cues allowed me to identify times where participants may have needed more time to consider their responses to the questions that I had asked, and also enabled me to observe participants’ emotional reactions during the interview, which gave additional contextual
information to their telling of their experiences (Kvale, 2009). For example, in my field notes, I recorded times where participants appeared amused, sad, or uncomfortable during the interview. For instance, when talking about the sexuality of older patients, I observed that some participants folded their arms and looked away, which appeared to indicate discomfort when talking about sexuality in relation to older individuals. Noticing participants’ body language also enabled me to ensure that my body posture continued to appear relaxed and open during face-to-face interviews; which I hoped assisted in building and maintaining rapport with the participant, and in potentially allaying any participant-held concerns that I may feel discomforted by their talk or emotional reaction (Minichiello et al., 1995). Further, a few participants, when offered the choice of either a face-to-face or phone interview, chose to take part in a face-to-face interview, explaining that they also appreciated having visual cues. Lastly, I also wondered whether my younger age had an impact on face-to-face interviews. In particular, I wondered whether it led to participants being more forthright in speaking about their concerns around talking to older patients and partners about sexuality, in comparison to if I was an older person conducting the interview. However, I noted that many of the participants who were interviewed over the phone also talked about their concerns about talking to older patients about sexuality, so my age may not have had much of an impact on the information participants shared.

Phone interviews, on the other hand, may have been preferred by participants due to the anonymity that this form of communication offers (Fenig, Levav, Kohn, & Yelin, 1993; Sturges & Hanrahan, 2004). Accordingly, this anonymity may have helped participants to share their experiences of discussing sexuality - a topic which is often considered taboo and private, and which therefore may have elicited feelings
one participant briefly stopped the phone interview within the first five minutes, so that she could close her office door to ensure privacy. This participant, who had requested I call her at work for the interview, did not wish her colleagues to know that she was participating in an interview to discuss health professional sexual communication; expressing her view that her colleagues would not approve of the notion that health professionals could have a role in discussing sexuality with patients. This participant was not alone in her concern, as some health professionals in another study have also reported concern that their workplace would not support sexual communication with cancer patients (Hordern & Street, 2007a). However, it is worth noting that the majority of participants in my study reported that they felt their colleagues would support their attempts to address sexual issues with palliative patients and their partners. Lastly, some participants reported that they chose phone interviews due to the convenience it offered, as reported in previous research (Sturges & Hanrahan, 2004). For example, it meant that they were able to do the interview at home and after work hours. Overall, however, it can be concluded that giving participants the choice of either face-to-face or phone interviews appeared to be appreciated by the participants; particularly by those who may have preferred the anonymity that the phone interview provided.

Analysis of Interviews

In this thesis, I conceive of the interview accounts as being co-constructed by the interviewer and the interviewee, as both participants during an interview draw on shared cultural knowledge as well as understandings of the nature of institutional

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1 I asked the participant if she would prefer to reschedule the interview so that she could call from a non-work location. However, the participant opted to continue with the interview.
structures to interpret the interviewee’s experience and co-produce meaning (Holstein & Gubrium, 2011; Yost & Chmielewski, 2013). In the context of this thesis, this included both myself and the participant drawing on existing constructions of sexuality, age, and illness, as well as the nature of clinical settings, to make sense of the interviewee’s experience.

In this vein, it is important to reflect on what I brought to the research process, and to examine how my personal experiences and understandings of sexuality may have shaped both the interview questions I asked as well as my interpretation of the participant accounts. Firstly, I have not experienced cancer myself, and subsequently have no direct experience of cancer and how it may affect my sexuality and relationship, and of how health professionals may or may not address these issues with me. However, this research has allowed me to recognise how potentially significant and devastating post-cancer sexual and intimate changes can be for cancer patients and partners, and particularly for those with advanced cancer. I also learned in doing this research that many cancer patients have reported not receiving information about the sexual changes that they may experience, and thus felt unprepared and unsupported when these changes occurred (Hordern & Street, 2007a). This has made me consider that if I were to experience cancer or another illness that will likely impact my sexuality in the future, that I would appreciate information from health professionals about what changes I may expect. Correspondingly, this personal position has also meant that in this thesis I argue that it is important for palliative care health professionals to raise and provide permission for patients or partners to discuss any sexual concerns, and to provide referral if appropriate. In saying that however, and as I will examine in the analysis chapters, I recognise that there are different levels of support that health professionals may
offer, and that palliative health professionals may not always be able to allay or resolve the sexual concerns of patients and partners. Similarly, I will also examine in the analysis chapters some of the material and discursive barriers to sexual communication that may not be easily changed or negotiated by health professionals. In other words, I understand that whilst sexual communication is important, it is not necessarily always easy to do.

I am not a trained health professional working in the field of cancer or palliative care, so do not bring that ‘insider’ perspective to this research. However, my clinical work and professional training in the field of family violence has made me aware that intimate partner violence is very common in Australia, and therefore likely to have been experienced by a number of palliative patients and partners. As such, I included prompts in the interviews to ask participants about whether they had worked with patients or partners who had experienced sexual violence, what issues patients or partners had experienced, and how they may have responded to these concerns.

Over the years I have also worked with services that offer support and advocacy to the Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ) community, and likewise have talked with family, friends and colleagues who have also been involved with this community in either academic or clinical support settings. This involvement, as well as the instruction I received on post-structuralism during my tertiary studies, and because I am an Anglo-Australian woman, have led me to conceive that sexuality and gender is predominantly understood through a heteronormative framework within Western societies. It has also facilitated my appreciation of the fluidity and diversity through which gender, sexual identity and sex itself can be expressed and constructed. Subsequently, these understandings
allowed me to recognise the dominant heteronormative discourse within our Western culture of sex as sexual intercourse (McPhillips et al., 2001), and to examine the participants’ positioning of palliative patients and partners within this discourse. I was then able to examine the implications this positioning had for palliative patients and partners who cannot engage in coital sex, who may not be partnered, and who may identify as non-heterosexual. These understandings also encouraged me to examine whether and how participants’ understood the gendered identities of palliative patients to be disrupted post-cancer.

As a female researcher, I was conscious that male participants may have felt more uncomfortable than female participants in describing the post-cancer sexual concerns of patients, or perhaps may not have felt comfortable talking about sexual norms such as the male sexual drive discourse. However, I noticed no differences in the disclosure of male or female participants during the interview, with both female and male participants offering detailed accounts of how palliative patients and their partners may experience post-cancer sexual changes. Rather, I believe that because participants were speaking about their professional experiences of addressing sexuality as clinicians, and were not asked to speak about any personal experiences of post-cancer sexual changes, that this factor was more influential in accounting for why both male and female participants gave rich accounts of their experiences of sexual communication.

Further, another factor which I believe enhanced participant disclosure was that I presented to participants as an educated person, given participants’ knowledge that this research formed part of a Doctoral degree. Thus participants may have regarded me as ‘equal’ to them in my capacity to reflect on and examine their professional experiences of sexual communication. Similarly, as I am experienced in
conducting research interviews in a professional manner, the tone of my interactions with participants was professional, which I believe also had the effect of enhancing disclosure.

During my interactions with participants, I did not offer my opinions regarding the role and responsibilities of health professionals in relation to sexual communication. I also did not overtly present myself to participants as having an ‘expert’ knowledge (as a researcher) around what I thought health professionals ‘should’ be doing in relation to sexual communication. Rather, I presented myself to participants at the beginning of interviews, and in the Participant Information Sheet, as a researcher who was interested in hearing their experiences of discussing (or not discussing) sexuality with patients and their partners. Similarly, during interviews I was conscious of having open body language, neutral facial expressions, and not commenting in agreement or disagreement in response to participants’ told experiences, in an effort to encourage participants to be open in talking about their experiences and opinions regarding health professional sexual communication. As such, I hope that my efforts in positioning myself as a non-judgemental researcher facilitated participant disclosure during the interviews.

In saying that however, some participants may have assumed that as a researcher exploring health professional sexual communication that I had taken up the position that all health professionals ‘should’ raise and discuss sexual issues with patients and their partners. Further, I did not give participants any information about my employment background, and none of the participants clarified my employment background at any stage before the interview. Accordingly, if participants assumed that I had no clinical palliative care experience, they may have thought that I did not have a shared, first-hand experience of the material, intrapsychic and discursive
barriers that health professionals can experience with respect to sexual communication, such as the time and privacy barriers that health professionals may face in hospital environments. Similarly, I did not disclose to participants whether or not I had experienced cancer, and so participants may have reached their own conclusions regarding this. For example, participants may have thought that my interest in this research was because I had a prior experience of cancer, and felt that health professionals should talk about sexuality. Thus, if participants held any of these perceptions of me, it may have led to participants speaking more about the challenges to sexual communication in order to explain or justify any limited sexual communication in their practice. Consequently, participants may have spent less time telling me about the palliative cancer care sexual issues they have recognised, and how they have responded to these issues. Nonetheless, I believe that this would not be so problematic if this was the case, as it would have enabled me to collect further data on challenges to sexual communication, and to examine how health professionals may at times use certain material or discursive barriers to excuse any avoidance of sexual communication.

The conclusion I reached following the analysis of all participant accounts, however, was that any power asymmetry during the interviews appeared to have limited overall impact on the richness of the data collected. Rather, I feel that in this research I have collected broad and detailed accounts of how participants responded to the sexual needs of palliative patients and their partners, and of the challenges they experienced with respect to sexual communication.
Transcription.

Fifteen of the interviews were transcribed by me, with the remainder transcribed by a commercial transcription service. All interviews, however, were quality and integrity checked by me, and some were re-transcribed to ensure consistency and accuracy of transcription if there were a substantial number of errors. In addition to these transcripts, interviewer field notes, which included my reflections or observations about the interview, were used to inform the overall analysis. The interviews were transcribed verbatim, and so a high level of detail was included in the transcripts, including pauses, disrupted words, interruptions, laughter, and fillers such as ‘um’ or ‘uh’. The extracts that are presented in the analysis chapters have been simplified for readability, where fillers and excessive use of colloquialisms, such as ‘um’ or ‘like’, were removed only when they did not convey any meaning.

I employed the following transcription conventions: Three periods, ‘…’, indicate irrelevant sentences and words which have been removed. Round brackets, “( )” were used to indicate sounds or pauses. Commas “,” indicate slight pauses in talk. Words, or the end part of a word, that were cut off in talk are indicated by dashes, ‘-‘. Words that have been CAPITALISED indicate that a raised voice was used to emphasise the meaning of a word. Square brackets, “[ ]” were used to insert words that are missing from talk. Words or sentences that have been italicised indicate parts of the account that I wish the reader to pay additional attention to, and in my interpretation of the account that follows the extract, I explain the importance of those italicised sections of the account. Sections of the account that are in italics, and that begin with the identifier, “interviewer”, indicate my talk in the interview account.
Thematic discourse analysis.

A thematic discourse analysis of the data was conducted, informed by a poststructuralist approach to discourse (Foucault, 1975, 1976) and a material-discursive-intrapsychic analytical framework (Ussher, 2000), situated within a critical realist paradigm. This analytical approach allowed for the data to be first organised within patterns or themes, and then allowed for a second level analysis of the organised data to be conducted, in which the discourses and subject positions were identified, and their implications for the subjectivity and practices of health professionals were examined. Accordingly, this component of my thematic discursive analysis of the interview data is akin to what Paul Stenner (1993) has termed a ‘thematic decomposition analysis’. This analytical approach also allowed for an examination of how health professionals’ talk contributed to the (re)production of discourse and influenced their practice (Edwards & Potter, 1992). As part of the secondary analysis, this approach also facilitated an examination of how health professionals’ negotiated the materiality of the patient’s cancerous body and the settings in which palliative care are provided - as these material factors are shaped through discourse - and the implications these material factors had for their practice and subjectivity (Yardley, 1996). Below I give a detailed outline of how the thematic discourse analysis of the data proceeded.

The ‘first level’ of analysis.

Data collection proceeded with the initial transcribed interviews being read by myself and my primary supervisor to identify and discuss emerging themes. This approach allowed me to address emerging themes that were not covered by the initial interview questions to be included in following interviews (Minichiello et al., 1995). Halfway through the data collection process, I performed an initial analysis on the
transcribed interview data, in order to develop a coding framework which reflected the major themes and patterns identified in the data (Stenner, 1993). This parallel process of data collection and initial coding of the data also allowed data collection to occur until theoretical saturation occurred, where the addition of new interview data did not create any new theoretical insight (Charmaz, 2006).

The development of a thematic coding framework occurred as follows (Stenner, 1993). Three transcripts from each health professional group; that is, physicians; nurses, social workers and psychologists or counsellors, were selected. These transcripts were read on a word-by-word, line-by-line basis, and codes and memos were added on to the transcripts to facilitate the analysis of the data. This stage of analysis involved first order coding, in which the codes that were applied were largely descriptive, and were as inclusive as possible. Examples of the first order codes that were applied included: ‘intimacy is relationships’; ‘intimacy is emotional connection’, and ‘sex is a low priority for patients who are sick’. Following this initial first order coding, the codes were checked against each other for commonalities and differences so that higher-order codes, otherwise known as themes, could be identified, and the first order codes subsumed beneath. For example, the first order codes, ‘ageist assumptions’ and ‘sex is a low priority for patients who are sick’, became subsumed under the code, ‘health professional assumptions and beliefs about sexuality’, which then became subsumed under the higher-order code, “barriers to talking about sexuality and intimacy’. Accordingly, this thematic coding of the data allowed for a coding framework (see Table 1) to be developed, in which the interview data was organised into meaningful themes (Stenner, 1993). The entire data set was then coded using NVivo, a computer program which enables organisation and storage of qualitative data.
These higher order codes formed the basis for how I went on to organise my analysis chapters. For example, the higher order codes, ‘Recognising the sexual and intimate needs and concerns of people with cancer and their partners in the context of cancer and palliative care’, and ‘Strategies for discussing and improving sexuality and intimacy’ were both used to structure the first analysis chapter (Chapter Four), where I present the data on health professionals’ experiences of recognising and responding to the sexual and intimate needs of palliative cancer care patients and their partners.

<table>
<thead>
<tr>
<th>Defining sexuality and intimacy</th>
<th>Intimacy is:</th>
<th>Relationships</th>
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<td>Meaning</td>
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<td>Touch</td>
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<td>Emotional</td>
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<td>Sexuality is:</td>
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<td>Sexual function</td>
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<td>Physical/pleasure</td>
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<td></td>
<td>Psychological (e.g., identity, attraction to others, sexual interests)</td>
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<td>Social/political context of sexuality</td>
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<table>
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<tr>
<th>Recognising the sexual and intimate needs and concerns of people with cancer and their partners in the context of cancer and palliative care</th>
<th>Emotional/psychological (e.g., self image/attractiveness, grief and loss of identity, sexual violence history)</th>
<th>Partner as carer</th>
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<tr>
<td></td>
<td>Physical (e.g., fatigue, pain, libido, disruptions to sexual functioning, hormonal changes)</td>
<td>Partners’ unmet needs</td>
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<td>Couple communication (e.g., self-silencing)</td>
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<td>Loss of relationships (e.g., anticipatory grief, withdrawal of patient or partner near death)</td>
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<tr>
<td>Comparing the hospital, hospice, and community care settings</td>
<td><strong>Pre-existing couple issues</strong>&lt;br&gt;Domestic and sexual violence&lt;br&gt;Relationships/intimacy re-prioritised</td>
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<tr>
<td><strong>Situational</strong></td>
<td>Lack of privacy in clinical settings&lt;br&gt;Medical equipment in the way&lt;br&gt;No double beds</td>
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<tr>
<td><strong>Hospital</strong></td>
<td>Focus on acute care/medical issues/medical interventions&lt;br&gt;Hospital setting and de-personalisation, loss of dignity&lt;br&gt;Expression of sexuality in clinical settings is inappropriate</td>
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<tr>
<td><strong>Hospice</strong></td>
<td>More holistic focus (i.e., focus on QOL) – visiting hours unrestricted, double beds available&lt;br&gt;Hospital limitations still present (e.g., privacy issues)</td>
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<tr>
<td><strong>Community care</strong></td>
<td>Patients’ ‘territory’ (e.g., photos around the home)</td>
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<tr>
<td><strong>Barriers to talking about sexuality and intimacy</strong></td>
<td><strong>Health professional factors</strong>&lt;br&gt;Age/gender of health care professional&lt;br&gt;Health care professionals’ ‘own baggage’&lt;br&gt;Beliefs and assumptions about sexuality (e.g., ageist assumptions; sex is a low priority for sick patients)&lt;br&gt;Skills and training</td>
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<td></td>
<td><strong>Patient factors</strong>&lt;br&gt;Patients do not raise sexuality&lt;br&gt;Patients are embarrassed to talk about/do not want to talk about sexuality issues</td>
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</table>
| Strategies for discussing and improving sexuality and intimacy | Overcoming personal barriers to discussing sexuality (e.g., changes in view of the importance of sexuality/intimacy to patients over course of career)  
Specific strategies used in initiating discussions of sexuality  
Strategies to improve sexual and intimate wellbeing  
Empathic listening and acknowledgement of experience  
Facilitating couple communication  
Giving space/privacy  
Permission giving  
Reducing pain/symptoms, providing medical treatments  
Encouraging non-coital practices and physical intimacy  
Whose role is it to discuss sexuality and intimacy?  
Health care professional’s perception of own role  
Discussing sexuality is a part of holistic care  
Thoughts on what aspects of sexuality they should discuss  
Health care professional’s perceptions of other health professional groups’ role  
Whose role is it to discuss sexuality and what aspects of sexuality should they discuss?  
Training/resources for  
Written information | Situational  
| Time constraints  
| No privacy in hospital setting for discussions about sexuality  
| No resources (e.g., no double beds, private rooms)  
| Feeling that the work environment is not supportive of attempts to address the sexual needs of patients |
The ‘second level’ of analysis.

Following the thematic organisation of the data, I drew on aspects of two discourse analytic approaches, namely Foucauldian discourse analysis and discursive psychology, to assist with the identification of the cultural constructions and subject positions that were present in the coded data, and the implications these available positions had for health professionals’ subjectivity and practices in relation to communication about sexuality. Although discursive psychology and Foucauldian discourse analysis have been viewed by some as two distinctly separate discourse analytic traditions (Burr, 2003; Ussher & Perz, 2014; Willig, 2008), others have argued that these analytical approaches need not be separate, but rather, that they can be synthesised and combined in analysis, as I have conducted in this thesis (Wetherell, 1998; Wetherell & Edley, 1999). Therefore, underpinning my analysis was the premise that discourses shape and produce subjectivity, that they are reflected in an individual’s use of language, and that individuals are active in producing discourses through their practices and talk (Stenner, 1993; Weatherall, 2000; Wetherell & Edley, 1999).

It is worthwhile noting that there is no ‘one way’ to do discourse analysis (Ussher & Perz, 2014), and so below I outline the aspects of Foucauldian discourse analysis and discursive psychology that I adopted in my analysis. I will then provide examples of analysed data which will demonstrate how I applied this discursive

<table>
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<th>health care professionals</th>
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<td>Checklists and screening tools</td>
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<td>Clinical supervision</td>
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<td>Referral options</td>
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analysis. Likewise, I will also explain, using examples, how I applied a material-discursive-intrapsychic analytical approach to interpret the data.

The central aim of Foucauldian discourse analysis is “…to identify the discourses operating in a particular area of life” (Burr, 2003, p. 170) and to understand how these discourses shape an individual’s experience, subjectivity, and practice. Foucauldian discourse analysis is also concerned with examining and understanding the power relations operating within discourses, and the implications of these for an individual’s behaviour: including what they can say, and when and how they say it (Willig, 2001). In this vein, I began my discursive analysis by locating the broader discourses present in the thematically coded data, and then examining the subject positions these discourses opened up (or disallowed) for health professionals (Ussher & Perz, 2014; Willig, 2008). With this, I recognised that individuals can take up, be placed in by others, or assign to others, various subject positions. These subject positions, located within larger social discourses, provide a framework for how the individual ‘should’ behave in a given social context. When individuals interact with one another, “the individual is not only acting as an individual, but as a collaborator in the positioning that occurs” (Howie & Peters, 1996, p. 59) as both individuals respond and behave from the way in which they have positioned themselves and the other. The theoretically informed questions which facilitated this component of the analysis included, ‘How is sexuality being constructed by health professionals, in the context of cancer and palliative care?}; ‘What discourses are being drawn upon by health professionals?}; ‘What do these constructions achieve for health professionals?}; ‘What subject positions are made available by these constructions, for both patients, partners, and health professionals?’; ‘What possibilities or limitations for sexual communication and
practice do these subject positions create for health professionals?`; ‘When might health professionals decide to take up or ignore these subject positions?’; ‘What consequences might these positions have for health professionals’ feelings, thoughts, and experience?’

Discursive psychology, on the other hand, is primarily concerned with the action orientation of people’s language. In other words, this approach is concerned with examining the performative and argumentative nature of language, and its constitutive role in (re)producing discourse; recognising that knowledge and social order is (re)produced through culturally shared meanings about words (Weatherall, 2000; Willig, 2008). As such, this approach can be used to examine: how individuals use language to construct a particular ‘social reality’ of themselves and events, and how they present this to others as factual; and what they accomplish by presenting this one particular version of reality (Coyle, 2007). Accordingly, when reading the data, I looked at health professionals’ use of metaphors and rhetorical questioning, and the ways in which patients, partners, colleagues, and palliative care health care settings were described (Edwards & Potter, 1992). Questions which facilitated this part of the analysis included, ‘How is sexuality being talked about by health professionals?”; ‘What language are health professionals using when talking about their patients, partners, and their colleagues?’; ‘How are health professionals talking about the spaces where they provide palliative care?’, “What discourses are being reproduced through health professionals’ use of language?”, and, “What are the discursive implications of using such language?”

During my inductive analysis of the coded data, I identified the following discourses: ‘biomedical discourse’; ‘discourses of hegemonic masculinity and femininity’, ‘ageist discourses’, ‘sex as functioning and performance discourse’,
‘palliative care discourse’, and the ‘psychosocial discourse’. Table 2 provides examples of the types of words or phrases from the participant’s accounts that were taken to be indicative of each identified discourse.

Table 2

*Examples of words or phrases from participant accounts that were indicative of each identified discourse*

<table>
<thead>
<tr>
<th>Discourse</th>
<th>Example</th>
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<tr>
<td><strong>Biomedical discourse</strong></td>
<td><strong>Example:</strong> Participants spoke about medically-trained health professionals having difficulty in responding to sexual concerns that diverged from sexual functioning. <strong>Example:</strong> Participants spoke about hospital settings being set up to primarily respond to physical, medical concerns, and/or hospital spaces were not conducive to providing ‘whole person care’.</td>
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<tr>
<td><strong>Hegemonic masculinity and femininity</strong></td>
<td><strong>Example:</strong> Participants may have spoken about men missing sex after experiencing post-cancer sexual functioning difficulties, but not women - which is indicative of the male sexual drive discourse. <strong>Example:</strong> Participants spoke about how removal of the reproductive organs could diminish women’s identities as a mother and woman.</td>
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<td><strong>Ageist discourse</strong></td>
<td><strong>Example:</strong> Participants described some patients as “elderly”, “spinsters”, and “oldies” – which contributed to the construction of older patients as asexual and easily offended by discussions of sex. <strong>Example:</strong> Participants spoke about finding it easier to talk about sexuality with younger patients than with older patients, because consistent with the ageist discourse older people are positioned as asexual and easily offended by discussions of sex.</td>
</tr>
<tr>
<td><strong>Sex as functioning and performance</strong></td>
<td><strong>Example:</strong> Participants positioned sex as coital sex. Accordingly, the sexual needs of non-heterosexual and/or un-partnered patients or partners were overlooked. For example, participants may not have discussed the sexual needs of un-partnered or non-heterosexual patients during interviews.</td>
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The biomedical discourse, as an example, opened up the subject position of what I termed the ‘good and expert’ health professional. Within the biomedical discourse, health professionals, and in particular physicians, are placed by themselves and by patients in a position of power, as ‘all-knowing’ experts with the power to heal and treat illness (Foucault, 1963). Thus, when health professionals deem themselves as lacking in knowledge about sexuality, they are able to legitimate any avoidance of discussing sexuality, as ‘good’ health professionals should only practice within their area of expertise (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). On the other hand, within this expert health professional subject position, health professionals may feel vulnerable or inadequate (an intrapsychic experience) if they deem themselves as lacking in knowledge about sexuality, which may function to close down sexual communication (Hautamäki et al., 2007; Magnan et al., 2005). As another example, the ageist discourse, which positions older people as uninterested in sexuality (Hordern & Currow, 2003), allowed health professionals to position some patients as ‘too old’ to be interested in sex. When older patients were
positioned in this way, their sexual needs were not recognised, and sexual issues were not raised with this group. Further, and to provide an example of the application of discursive psychology, the way some health professionals talked about older patients also contributed to this positioning of older patients as asexual. For example, health professionals described some patients as ‘elderly’, ‘spinsters’, and ‘oldies’ – which contributed to the construction of older patients as asexual and easily offended by discussions of sex, as I will present and explain in Chapter Five.

Consistent with my adoption of a material-discursive-intrapsychic approach, I also examined accounts of how material factors may have shaped health professional practice and subjectivity. In particular, I examined how the materiality of the health care settings in which health professionals worked shaped their practices and subjectivity in relation to recognising and responding to the sexual needs of patients, and how the materiality of these settings is also shaped by discourse. The questions which guided this analysis included: ‘How might the structure of clinical settings, such as consult time and privacy, open up possibilities or create limitations for health professionals communication and practice in relation to sexuality?’, and, ‘How might the materiality of these settings be shaped by discourse?’. As an example, the biomedical discourse, hegemonic within hospital settings, was identified as having a key role in shaping the material structure of hospital settings, which had implications for health professionals’ capacity to recognise and respond to the sexual and intimate needs of hospital patients – an issue which will be explored in Chapter Six.

Health professionals’ understanding of the materiality of the patients’ cancerous bodies, and the role of this in shaping their practice around sexual communication was also explored. This included an examination of how health professionals constructed the patients’ cancerous body through available discourses.
Questions which guided this analysis included, ‘How might health professionals’ knowledge of the material impact of cancer and having a life-limiting illness shape their positioning of the patient and the patients’ sexual needs?’, and, ‘What discourses did health professionals draw on to construct the patient’s cancerous body?’. Consistent with an inductive approach to data analysis, after reading the coded data, I also located theories which assisted with my interpretation of the data (Charmaz, 1995). For example, theories around the meaning and experience of chronic illness, such as Michael Bury’s (1982) paper on ‘Chronic illness as a biographical disruption’, were found relevant and helpful in interpreting some health professionals’ talk which related to recognition of how palliative patients experienced having cancer and a life-limiting illness.

At this point I also want to acknowledge that the consideration of discourse here, in these guiding questions that I used to examine the role of material factors in shaping health professional experience and practice, may seem repetitive in light of the process of discursive analysis I followed and outlined earlier. However, this repetitiveness reflects the recursive process of my analysis – I found that ‘doing’ this analysis in what might seem a ‘repetitive’ and ‘layered’ way, enabled me to explore the relationship and interaction between the material, discursive and intrapsychic factors (in accordance with a material-discursive-intrapsychic approach), rather than examining these factors in isolation to one another.

Finally, consideration was given to intrapsychic factors, and how they interlinked with discursive and material factors to shape health professional sexual communication. As may already be apparent at this point in the explanation of the thematic discourse analysis I conducted, some intrapsychic factors were interpreted, and discussed by me, in terms of the intrapsychic experiences that arose from health
professionals’ negotiation of material and discursive factors. For example, health professionals’ positioning of older patients as not interested in sex may have contributed to health professionals feeling embarrassed or uncomfortable at the thought of raising sexuality, let alone discussing this topic. However, other intrapsychic factors that were examined in my analysis included consideration of how health professionals interpreted previous experiences of communicating about sexuality, and how these interpretations might have made future sexual communication easier or more difficult. For example, some health professionals’ recounted positive previous experiences of talking about sexuality, which increased their confidence in relation to discussing sexuality, and assisted in their positioning of sexuality as an important issue to discuss with patients post-cancer. Health professionals’ understanding of the emotional wellbeing of patients and partners’ post-cancer, and how patients’ and partners’ emotional wellbeing might have impacted their sexual wellbeing and practices, was also explored. To illustrate, some health professionals talked about the psychological distress that some patients experienced as a result of increasing bodily deterioration, and spoke about how this experience of psychological distress contributed to patients’ withdrawal from sexuality and intimacy – an issue explored in Chapter Four.

Conclusion

In this chapter I have explained how the methodological framework I adopted has facilitated my analysis of how material, discursive, and intrapsychic factors shape health professionals’ practice and experiences in relation to sexual communication. In the following chapters I present the results of my analysis. Chapter Four will explore health professionals’ experiences of recognising and responding to the sexual and intimate needs of palliative care patients and their
partners. Chapter Five will examine the discursive patient-centred barriers that led some health professionals’ to position particular groups of patients and their partners as not having sexual concerns that needed to be discussed. Chapter Six will then examine how the biomedical discourse shapes the practices of health professionals, and also how the different health care settings in which palliative care is provided can either aid or constrain health professional sexual communication. Finally, Chapter Seven will provide a conclusion to the thesis by way of reviewing and discussing the implications of these research findings.
Chapter Four: Recognising and Responding to the Emotional and Relational Aspects of Sexuality and Intimacy in Palliative Cancer Care

The majority of health professionals I interviewed adopted a position which recognised that sexuality and intimacy continued to remain important to palliative care patients. Accordingly, they positioned responding to sexuality and intimacy as a part of their role. However, for some health professionals, sexuality and intimacy was positioned as a topic that they did not always feel comfortable, or willing, to discuss. Yet, through personal and professional experiences, some health professionals reported that they overcame this discomfort and reluctance to discuss such issues. This is the first issue that will be discussed in this chapter. I will then move on to discuss the specific emotional, physical, and relational concerns of people with cancer and their partners that health professionals acknowledged and responded to. Firstly, participants recognised that intimacy can be re-prioritised for end-of-life cancer patients and their partners, with intimacy also positioned as central to providing continued hope, self-worth and meaning to palliative care patients, as well as providing comfort when sick. Secondly, participants also observed that, conversely, patients and couples may withdraw from sexuality and intimacy at the end-of-life due to anticipatory grief. Thirdly, health professionals also recognised how post-cancer sexual changes and advancing bodily deterioration can often negatively impact the sexual practices and gendered identities of people with cancer, and can cause distress and disruption to the sexual lives of patients and their partners. Finally, I will discuss how health professionals’ responded to palliative patients and partners who were at risk of, or who were experiencing, sexual coercion and violence, perpetrated by their intimate partner.
Positioning Sexual Communication as Part of the Palliative Care Health Professional Role

Most participants positioned sexuality and intimacy as central to the well-being of palliative care patients and their partners, and that it continued to remain an important part of their lives. As Beth, a nurse, explains, “it’s a natural part of everybody’s life and well-being. I don’t think that just because you have a diagnosis or you have a life-limiting illness that changes”. Susan, a bereavement counsellor, also spoke about the importance of intimacy and sexuality, “We gain such comfort from closeness and togetherness and intimacy. So when we’re really sick, to have that physical comfort, when life is so precarious, I think it’s very life affirming”. Finally, Heather, a nurse, also positioned sexuality and intimacy as important to palliative care patients and their partners:

It [having a terminal illness] doesn’t mean that the person becomes any less of an intimate or sexual person, perhaps it may be that even in the last moments of death, that having your partner lie beside you, and holding you, is something that is very meaningful.

Given this, most participants positioned communicating and responding to sexuality and intimacy as a part of their professional role. For example, Heather, a nurse, said that, “I think it’s imperative. I think that to ignore that talk, to ignore that part of someone, or to not consciously want to go there, that that is not doing the very best that you can for that person.”

These accounts reflect previous literature, in which other health professionals have recognised the sexual and intimate needs of palliative care patients, and have positioned addressing such needs as an important part of their clinical role (Haboubi & Lincoln, 2003; Lindau et al., 2011; Saunamaki et al., 2010).
However, for some participants, sexuality and intimacy was positioned as a topic that they did not always feel comfortable, or willing, to discuss. Yet, through personal and professional experiences, some health professionals reported that they overcame this discomfort and reluctance to discuss such issues. For example, Sara, a social worker, reported that, “Because I value it as being important, that helps me to overcome the anxiety”. Further, Judy, a bereavement counsellor, explained that:

Just talking from my own experience of my husband dying, again, our physical relationship was more important than ever, because he couldn’t speak, so we couldn’t communicate in that way. And so the tenderness that we shared at that time was so precious.

Finally, Madeline, a psychologist explained:

What helped with the shift for me, was realising in some ways the issue of sexuality and intimacy isn’t any different to any of the other issues that a patient’s dealing with in this setting. So you know, I was very comfortable talking with them about mortality, and yeah, basically life and death, and all those big issues which are quite scary and confronting for patients and families. And then I guess the realisation for me is that sexuality and intimacy are all tied up in with that. And just really realising from experience that actually those conversations usually go really quite well and the patient usually finds them quite helpful. They often express relief that they’ve been allowed to talk about it and have those questions answered.

These accounts illustrate that the adoption of a psychosocial discourse, where sexuality is seen as a central and important part of the person’s life, and post-cancer changes are recognised as having emotional, physical and relational implications for people with cancer and partners, can assist health professionals to legitimate
discussions of sexuality as part of their clinical role (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Further, these accounts concur with previous research, in which other health professionals have reported positive experiences following their efforts to discuss sexuality (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Such positive experiences assist in building health professionals’ confidence to address sexuality (Hordern et al., 2009; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013), and in challenging the myth that most patients and partners would consider it inappropriate for health professionals to raise sexuality with them – an assumption that health professionals have reported making in previous research (Hordern & Street, 2007b; Stead et al., 2003). I will now go on to discuss the specific cancer and palliative care sexuality and intimacy issues that participants positioned as important, and discuss how they responded to these issues.

“Probably More Important Than Ever”: Intimacy Provides Continued Hope, Self-worth, and Comfort When Sick

Intimacy, whether expressed as an “emotional connection” or as non-sexual touch between partners, was positioned by participants as being central to maintaining and enhancing the quality of life and relationships of palliative cancer patients and their partners, who were confronting the impending death and advancing illness of the patient. Accordingly, health professionals reported that supporting and strengthening intimacy between couples was a key part of their role. In particular, many health professionals explained that intimacy was “a way of maintaining hope”, meaning, and continued “self-worth” for palliative patients. As Linda, a psychologist, explains, “people may have lost out on life roles, but they may always be able to be a partner, always able to have an intimate relationship”. Ken, a palliative care physician, also highlights the importance of intimacy in “maintaining
hope” for people following diagnosis of a life-limiting illness, and explains that supporting intimacy is a key part of his work:

Intimacy, I talk about quite often. Pretty much all the time in fact. It’s a way of maintaining hope for people. And, you know, really the analogy is when people have a serious illness with a limited prognosis, it often is a bit of a shock when they’ve come to that, you know, determination or somebody's told them that. And we all have our own sort of fantasies, if you will, about how our life is going to be you know. And if - when you're younger, you think about having a family and - well, a lot of people do anyways. And how that’s going to be and, when you're my age, you're thinking about retirement and then how that’s going to be. And when you are diagnosed with something that drastically changes what that future story is going to be like.

According to Bury (1982), the diagnosis of a disease leads to “a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging” (p.171). Ken’s account illustrates that the diagnosis of a life-limiting illness constitutes a “drastic” biographical disruption in the patient’s life. As Ken goes on to explain in the following account, appreciating and “preserving” intimate relationships is positioned as an important part of his role, as it assists patients to reconstruct a meaningful “future story”:

Then how can you help people rebuild their future story and still maintain some hope? And that's where it gets into preserving those relationships and - and allowing them to be able to appreciate them to their fullest. And I think intimacy would be of increasing importance because I no longer have work and other things to help me to add to my sense of self-worth. So my self-
worth now becomes totally wrapped up in being able to express that intimacy and appreciate those relationships and be able to gracefully accept the care and support because I'm no longer an independent functioning member of society…And beyond some reassurance about the symptom relief and the control of physical symptoms the thing that I think takes on the greatest importance is - is in fact is being able to share and appreciate those personal relationships.

Ken’s account highlights two issues which follow on from the biographical disruption that diagnosis of a terminal illness can bring. Firstly, with increasing dependency on others to provide care and support, norms of mutual reciprocity and dependency can be challenged (Bury, 1982; Lawton, 2003). However, as Bury (1982) highlighted, strong social relationships, and the willingness of others to provide care, can assist people with chronic illness to adapt to their disrupted life. The second issue which Ken draws attention to is the health professional’s role in the facilitation of meaning-making and preservation of hope for patients facing impending death. Narrative reconstruction is a conceptual strategy which follows a biographical disruption from illness, which allows the individual to regain some autonomy, a sense of order and to “reaffirm the impression that…the self has a purpose or telos” (Williams, 1984, p. 179). For people facing impending death, their task turns from the curative discourse of ‘life and death’, where hope is in the possibility of survivorship, to the discourse ‘of meaning in life’, in which hope transitions to “the formulation of meaning for the life that is ending” (Eliott & Olver, 2007; Little & Sayers, 2004, p. 1333). The task of meaning-making is instrumental in preserving hope, and in contributing to assist the patient in achieving ‘a good death’. It has been recognised that strengthening, or at least preserving nurturing and loving
relationships, is a primary criterion in facilitating ‘a good death’, and in providing meaning and hope (Choichinov, 2006; Little & Sayers, 2004; McClement & Choichinov, 2008). Indeed, David, a bereavement counsellor, explains that couples who are able to strengthen their emotional connection by together facing the “impending reality” of the patient’s death, tend to “fare better”.

Couples that are able to go to that place and who are able to in a sense realistically acknowledge the fact that death is coming, then – and then are able to go into these deeper places and have those conversations, tend to do and fare better. And so intimacy and sexuality, the intimacy is around being able to face with courage really, the impending reality and to face the unfaceable. And to be able to hold each other in that space and to be present to each other in that space and to then be able to say those deeply personal things that may not have been said, or may have been said in the past but aren’t reiterated, you know, are stated again and stated with greater intent and greater depth and meaning.

This recognition of the importance of preserving and supporting intimate relationships was also reported in a study of terminally ill patients, who described that, along with adequate symptom control, strengthening relationships was a primary concern (Singer, Martin, & Kelner, 1999). Additionally, the accounts that health professionals provided in my study recognised that physical acts of care, and non-sexual touch, were an important component of deepening intimate relationships.

As David goes on to illustrate:

I think often the physical aspects of that can often follow, so I would hear the stories of people who describe the very simple, often very simple acts of physical care that I think are an expression of that intimacy and in some sense
a deep kind of sexuality, you know a kind of meaningful sexuality. And that might be things like the bathing, acts of bathing or simple things like you know, putting moisturiser on a person’s lips, who might be dying.

Likewise, Veronica, a social worker, also highlights the value of non-sexual touch, as well as sexual touch, in providing comfort:

Just to share the comfort of sexual intimacy because of the sadness and the fear and all of those things. Whether it’s actually having sexual intercourse, or whether it’s just by touching and being emotionally close, I think, would be essential.

Finally, Julia, a palliative care physician, also speaks about the importance of non-sexual touch in providing comfort:

The human touch. I think, flesh on flesh is very comforting. And particularly if it’s been a feature of a relationship for a long time. But even if it’s not flesh on flesh, I think just human touch is – is of great comfort, when people are suffering.

All of these above accounts concur with studies examining the meaning of sexuality and intimacy to palliative care patients, in which it was reported that patients placed a greater focus on the emotional connection expressed through sexuality and “…on verbal and non-intercourse forms of intimacy” (Lemieux et al., 2004, p. 632), such as non-sexual touch, than on sexual activities (Taylor, 2014). These expressions of intimacy were instrumental in creating a sense of closeness and solidarity with their partner. This is an issue that has also been identified by others who argue that at the palliative stage of illness, people with cancer often reprioritise their needs, with the need for connection becoming more significant than physical expressions of sexuality (Cagle & Bolte, 2009; Hordern & Currow, 2003). Likewise, my study
supports the notion that palliative care health professionals recognise that expressions of intimacy can take on greater importance during the palliative stages of illness.

Whilst the re-prioritisation and deepening of intimate relationships during the palliative care stage is an important and positive experience for many couples, it is also important to note that following the death of the patient, bereaved partners may also require support from health professionals, as partners may struggle to “make sense of” their experience of renewed intimacy. As Andrea, a bereavement counsellor, explains:

So I think through a palliative illness, it’s a time of crisis, but, yeah, has got the power to bring the intimacy of a relationship closer. I’ve seen it do that towards the end of people’s lives, that, no, it’s not been about sex, it’s been about intimacy that has brought them close. The going back to the earlier parts of their lives and the intimacy around that. But then when the person has died, grappling with having had an intimate time, that probably had they not known the person was going to die, they may not have ever returned back to that intimacy. So that intimacy, being very special at that point in time and talking about feeling like they’ve fallen in love with someone all over again. Then the person dies, and then they’re in counselling, trying to make sense of, “What was that?” “What actually was that? Because at the beginning of the relationship we fell in love, we had this amazing sex life, everything drifted apart, and then we became intimate again and fell in love again, around the crisis of illness and death.” “What part of that was real? Is it all real?” What – so I’ve seen that in counselling.
Other studies looking at the experiences of carers have reported on how intimate relationships may be strengthened during the cancer journey, or when confronting end-of-life issues. For example, and in agreement with Andrea’s account, above, some carers have reported increased feelings of ‘togetherness’ and ‘closeness’ with their partner, by virtue of facing imminent death, and through spending increased time together prior to the patient’s death (Wong, Ussher, & Perz, 2009). Further, a number of studies have found that carers of cancer or terminally ill patients can find the act of caring to a positive experience, with many positioning caring as a privilege, and a way of expressing their love for their partner (Grbich, Parker, & Maddocks, 2001; Hudson, 2004; Ussher, Sandoval, Perz, Wong, & Butow, 2013; Wong et al., 2009). These studies confirm that couples can have positive experiences during the end-of-life period, with the potential for increased feelings of togetherness and closeness. Yet, as Andrea’s account also illustrated, partners may experience difficulty processing this renewed sense of intimacy following the death of the person with cancer, demonstrating that offering professional support to bereaved partners may be important to some who experience this (Grbich et al., 2001).

However, no previous research has identified that bereaved partners may experience difficulty processing a renewed sense of intimacy following the patient’s death, and so this is an issue that could be explored in future research, along with the role of health professionals in providing support for this issue.

Although the health professionals I interviewed recognised that for some couples facing the reality of impending death intimacy can be re-prioritised and strengthened, they also recognised that there are also couples who experience the opposite. Whilst some couples may still desire intimacy, the health professionals in my study recognised that the intimate carer may begin to disconnect in anticipation
of the grief the carer will experience when the patient dies, or that the patient may begin to disconnect to “cope” with the loss of their impending separation from their partner (Redelman, 2008), an issue which I will now move on to discuss.

**Anticipatory Grief and Coping with Impending Separation: Patient or Partner**

**Withdrawal from Intimacy and Sexuality**

In my study, many health professionals positioned patient withdrawal as a defence coping mechanism to explain why patients and/or partners withdrew from sexual and intimate contact at the end of life. For example, Fiona explains that, “some people do seem to be getting ready for the departing, and maybe the emotions are getting too strong and they pull back”. Likewise, Carla, a social worker, explains that patient withdrawal is “a protective thing for themselves”, and details the impact of this withdrawal on intimate and sexual expression:

> I think it’s part of the dying process and it’s too painful to stay too connected. So they sort of say their goodbyes and start to, you know, disconnect and shut down and want to see less people and engage less with…And so there’s a withdrawal of that which I’m sure would affect their sexual relationship and intimacy at that time. You see that quite a lot. I think it’s a protective thing for themselves. It’s just too painful and they’re just too tired and it’s just part of the leaving process. Which I guess sex is about connection and engagement with someone. So they’re actually trying to do the opposite and leave the world.

Other health professionals noted the impact of remaining “curative focussed”, rather than focussing on sexuality and intimacy. For example, David, a bereavement counsellor, talks about the “great lament” a bereaved husband held after the death of
his wife, because he felt that accepting his wife’s death and using the remaining time to have “those really important conversations” would invite her death to occur:

I think there are some couples that – where people, they tend to want to remain very cure focused and will find it very difficult to want to be able to go to those places where those really important conversations could be held and need to be held. And so they will want to focus on the cures or the strategies toward cures and often their – the intimacy or their needs will be expressed in frustration and in trying to be active, and then trying to seek out alternatives. And as a bereavement counsellor, I hear the different aspects of those experiences from people and, so there’ll be some people who will be wanting to hold onto a faith or a miracle that’s going to happen, or some kind of intervention that’s going to stop this from happening. I know one guy recently who lost his wife and the cancer was very strongly focused and they got married and there was kind of all these strong beliefs that she would be cured, and then after the death his great lament around some of the things that he wished he had communicated and said to her that he didn’t have, or didn’t do because you know, he was fearful almost that if he were to raise those sorts of things it would almost be like giving up hope and then somehow inviting her death to occur.

In David’s account, above, the male bereaved carer adopted an active coping strategy - remaining curative focussed - whilst appearing to avoid the emotional work, which included having those “really important conversations” with his partner. Previous research examining gendered caring differences amongst cancer carers has found that men are more likely than women to adopt active coping strategies. For example, it has been found that men are more likely to focus on ‘mastering’ practical caring and
emotional tasks, such as facilitating medical care and attempting to maintain a positive mask in the face of cancer, whilst both avoiding and experiencing difficulties in dealing with their own or their partners’ emotional reactions to cancer (Ussher & Sandoval, 2008; Ussher, Sandoval, et al., 2013). As the researchers in one of these studies noted: in the short-term such an approach can be helpful to men, as it allows them to position themselves alongside masculine ideals of stoicism and rationality, rather than expressing sadness and other forms of distress, which is commonly positioned as feminine and ‘weak’ (Ussher & Sandoval, 2008). However, in the long-term, as David’s account illustrated, remaining curative focussed and not doing this emotional work is often not adaptive. Rather, it has been found to be associated with both members of the couple dyad experiencing greater cancer-related distress during the patient’s illness (Hagedoorn, Kreicbergs, & Appel, 2011), and with partners experiencing greater distress in bereavement (Ussher, Perz, Hawkins, & Brack, 2009). Further, it can contribute to the emotional concerns of men being overlooked by health professionals and health services, with supportive services more likely to be provided to women who outwardly express distress (Thomas, Morris, & Harman, 2002; Ussher & Sandoval, 2008). As such, this account and previous research suggests that it would be helpful for health professionals and health care services to recognise potential gendered differences in coping styles. Such recognition would assist in ensuring that opportunity to take up emotional support is provided to men. Finally, health professionals may also be able to facilitate men to do emotional work by assisting them to challenge the dominant construction of masculinity that equates male expressions of emotional distress with being weak and ‘unmanly’ (Ussher & Sandoval, 2008).
Moreover, the above accounts are confirmation of previous research which reported that patients and partners may withdraw from sexual and intimate contact at the end of life due to anticipatory grief, or, as David described, by remaining curative focussed. For example, in Taylor’s (2014) study, a bereaved wife reported that although she was willing to give oral sex to her partner who was dying, she felt unprepared to have intercourse with him, saying that, “the feeling that having sex brought me was just a constant reminder that I was going to lose [him] soon” (p. 443). Acknowledging that withdrawal from emotional or physical intimacy can occur due to anticipated grief and loss, many health professionals I interviewed shared times where they addressed this issue, through facilitating communication between couples. As Madeline, a psychologist, explains:

But then on an emotional level, some, you know, a number of patients I’ve spoken with have started withdrawing, not just from the sexual act, but just even intimacy on the level of holding hands or giving a hug or touching their partner, because they are under the misguided belief that if they start emotionally and physically withdrawing from their partner, that will somehow cope with the separation, when they die, more easily, you know. So, actually just having that conversation with the patient, about that’s not how it works, and getting them to open up that discussion with their partner about what they’ve been doing and what their thinking is around that then often leads to an improvement in that situation. You know, they get to hear from their partner that that’s the last thing they want them to be doing, and nothing can prepare them, and they want to be able to hold onto them as closely as they can until the time they die, and that often improves the situation.
This account concurs with previous authors who have also supported the view that health professionals can address withdrawal due to anticipatory grief by facilitating communication between couples (Redelman, 2008; Stausmire, 2004). Additionally, this account also illustrates the self-silencing practices that one or both members of the couple might engage in, through which either patients and/or partners suppress their own feeling states or needs in an effort to ‘protect’ and care for the other partner (Badr & Carmack Taylor, 2006; Ussher, Wong, & Perz, 2011). However, as other research has confirmed, self-silencing practices are often associated with couples experiencing higher levels of relational distress and poorer coping during the cancer illness. Whereas, conversely, partner disclosure has been found to reduce relational distress, as well as increase perceived feelings of intimacy, care and understanding between the couple (Badr, Acitelli, & Carmack Taylor, 2008; Manne et al., 2004). This has led to the suggestion that it may be helpful for health professionals to employ couple-focused interventions with the intention of improving couple communication and partner disclosure. Indeed, other research has found that couple-focused interventions employed by health professionals are effective in reducing couple distress, and in improving coping and sexual adjustment as well as in later assisting in reducing partner distress during bereavement (Scott, Halford, & Ward, 2004; Ussher et al., 2009). Such findings confirm the idea that palliative care health professionals can provide support that will improve couple communication.

The accounts within this theme identified that participants recognised that patients or partners may withdraw emotionally and physically from each other in an effort to cope with the impending death of the patient, or in the case of patients, in an attempt to help their partners cope more easily with their death. Participants in my study acknowledged that self-silencing practices and withdrawal from each other
often negatively impacted on relationships; often meaning that opportunity for
important emotion work or continued expressions of intimacy were missed. As such,
this often led to either or both members of the couple dyad experiencing distress or
feelings of regret. A number of participants reported successfully addressing this
issue by facilitating communication between couples. This intervention therefore
confirms previous research which has found that couple-focussed interventions that
aim to improve couple communication, and which counter self-silencing practices
and any avoidance of emotion work, often improve relationships and reduce distress
(Dieperink et al., 2015; Perz, Ussher, & The Australian Cancer and Sexuality Study
Team, 2015; Ussher et al., 2009).

**Recognising Embodied Experiences: Unbounded and Abject Bodies**

**Breaching discourses of normative functioning and gender.**

All of the health professionals I interviewed recognised that changes to the body
caused by cancer and cancer treatments could create experiences of abject
embodiment. The ‘abject’ body is “a messy, polluted, sick, and damaged body”
(Waskul & van der Riet, 2002, p. 487), a body which falls outside normative
boundaries of bodily control, and which can remove the person from social
constructions of normative femininity and masculinity (Parton, 2014; Parton et al.,
2015). Changes to the body which were perceived as producing experiences of abject
embodiment included changes to both the appearance and functioning of the body,
such as, “scars, ostomies, implanted devices, or loss of hair or loss of weight” (Heidi,
social worker), “having symptoms such as nausea and pain” (Helen, a nurse), “losing
functioning of a limb” (Fiona, nurse), and “having equipment hanging off you” (Ken,
palliative care physician). Participants acknowledged that the embodied experiences
of these abject changes often caused distress for people with cancer and their
partners, including “embarrassment”, “shame” and “humiliation”, and often impacted the “willingness” of patients or couples to engage in sexual and intimate activities. For example, Fiona, a nurse, recalls the reaction of a man who was treated for lymphedema:

I’m really aware of, because of my work with lymphedema, how people really hate how their legs get huge and their arms get huge. And, I saw a man recently who was huge, from his toe to his nipple line, and they put in a drain which literally drained all the fluid from his body and he died shortly after that. But he was so thrilled that he looked normal again and he died. So I think that, what the illness does to the body could affect somebody’s willingness to be open and to be intimate with another person.

Fiona’s use of the phrase “he was so thrilled that he looked normal again”, signifies recognition that the patient, “huge” with lymphedema, had reportedly positioned his body outside of ‘normality’. This suggests an experience of “dys-embodiment” (Williams, 1996, p. 23), a term used to describe the discordant experience of having a body and self which is dys-functional, ill, and does not match “with one’s desired presentation of the self” (Gilbert et al., 2012, p. 604) (see also Kelly & Field, 1996).

Additionally, participants acknowledged that bodily changes did not need to be visible in order to have an impact on the patient’s embodied experience of themselves. As Sabrina, a palliative care physician, reports, “there is body image even for people who don’t have visual tumours. They do still have a mental image of what that cancer is doing to their body.” This account illustrates the experience of the ‘dis-appearing’ self, where awareness of illness causes the taken-for-granted ‘disappearance’ of the body to profoundly appear (Leder, 1990). In our everyday lives, our bodies are largely phenomenologically absent (Leder, 1990). However, as
Williams (1996) has argued, “only when things ‘go wrong’ with our bodies, whether through illness or various other forms of bodily ‘betrayal’ and ‘resistance’, do they become ‘problematic’ as the thematic object of attention” (p. 24, emphasis in original). Here, Sabrina acknowledges that merely the presence of illness in the body signifies, to the person with cancer, that their body is ‘dys-functional’, and outside of boundaries of normality (Williams, 1996). Thus, this account indicates that cancers that do not cause visible changes, or that perhaps may not cause discernible physical sensations and symptoms, can still have the potential to create an experience of sexual dys-embodiment, and may cause distress, for patients.

*Post-cancer bodily changes and changes to sexual practices.*

Changes that affected the sexual organs were identified as having “obvious” negative implications for sexual practices. For example, Pamela, a social worker, spoke about a woman who missed sexual intercourse, because of changes her husband experienced following prostate cancer:

A woman whose husband is dying, and he’s got prostate cancer. She approached me several months ago saying the lack of sex in their relationship was a big issue for her. Because of his cancer, he was not capable of sexual intercourse.

Sarah, a social worker, also spoke about how men and women may lose interest in sex, because changes to the “reproductive area” can make sex painful:

I think some cancers that are evasive to parts to the body like breast cancer, or any cancer of the reproductive area can make it either painful for a person, or, painful for a woman to the extent that they know it inhibits their interest in sex. And I think that men with breast cancer, or men with penile or scrotal cancers and things like that, things like that could have the same reaction.
Lastly, Carla, a social worker, recognised that cancer treatments can diminish libido:

I remember working with one couple who were really young. They had their wedding anniversary coming up and they booked a whole, you know, romantic, you know, weekend away and it was the spa and they were really hoping to have a – a good time and sexually. And something happened – he drank alcohol as well as his drugs that night and he just – you know, completely, you know, sort of passed out [laughs]. She was saying. “Oh, my God”, you know [laughs]. “So much, here we got the expensive hotel to be romantic. You know, the night the kids were looked after and” – and, yeah, so it just was the medication and everything mucking up his - his ability. God knows what effect all the drugs have on people’s libido. I imagine significant.

Indeed, there is an abundance of research that confirms that post-cancer changes affecting the sexual organs often have an adverse impact on the sexual practices of patients and their partners (e.g., Arrington, 2003; Chapple & Ziebland, 2002; Gilbert et al., 2010b, 2011). For example, women with breast cancer or gynaecological cancers have reported experiencing physical changes such as, diminished sexual desire or interest, vaginal dryness and painful intercourse (Gilbert et al., 2010b, 2011; McClelland et al., 2015; Pieterse et al., 2006). Likewise, men who have prostate or testicular cancer have reported experiencing physical changes such as, erectile dysfunction, incontinence, and diminished sexual desire (Bertero, 2001; Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Hanly, Mireskandari, & Juraskova, 2014).

Further, and in accordance with some of the above health professional accounts, some people with cancer and their partners have reported feelings of missing sexual
intercourse due to the physical changes following cancer or cancer treatment that render coital sex impossible (Gilbert et al., 2012). Indeed, when couples are no longer able to have sexual intercourse, other forms of physical intimacy may cease as well, due to the perception that intimate acts will inevitably lead to sexual intercourse (the coital imperative), or because, within many heterosexual relationships, non-coital sex is not seen as ‘real’ sex (Gilbert et al., 2009; Hughes, 2000), given the dominant social construction of sexuality that positions ‘real’ sex as vagina/penis intercourse (McPhillips et al., 2001). However some couples are able to renegotiate their post-cancer sexual practices, by resisting phallocentric notions of sexuality, and engaging in other forms of sexual expression (Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). This included engaging in non-coital practices, such as oral sex and masturbation, or by prioritising intimacy, and expressing this through cuddling, kissing, and massage. A few health professionals interviewed in my study recognised that they could play a role in assisting couples to renegotiate their sexuality in the context of cancer, and gave examples of how they achieved this. This included, providing medical treatments or other interventions that might make sexual intercourse possible; and encouraging couples to explore other ways of engaging sexually. As the account of Madeline, a psychologist, illustrates,

When you start getting down to talking to patients about how they could try to engage in other sexual activity apart from intercourse, or use lubrication, or spend longer on foreplay, you know, getting down into suggestions and things like that.

Linda, a psychologist, also reported that she assists couples to look “at other options other than intercourse, because if people have a broader repertoire, that seems to assist”. Similarly, Dianne, a social worker, talked about “teaching” a couple “about
the relaxation techniques and touching”, after a female patient reported that she still desired sexual contact, yet could no longer have sexual intercourse following surgery. Also, Carla, a social worker, gave an example of a time she assisted a woman with cancer, who was experiencing low energy and diminished libido, to communicate her sexual needs with her husband:

I’m thinking about that lady who was saying to me she felt bad because she knew her husband wanted a physical relationship, but she just had no energy and so we talked about, strategies about, you know, explaining that to him…And she could indicate to him that she still liked the touch that came with that [sex], but she just didn’t have libido anymore, or energy.

These accounts demonstrate that some health professionals took a broader view to understanding the re-negotiating of sexual practices. In other words, they acknowledged that responding to diminished sexual activity required more than simply treating sexual ‘dysfunction’, but could also involve assisting couples to find other ways of maintaining sexual contact. This finding confirms recent research, in which other health professionals reported that they provided education about alternative sexual practices (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Accordingly, this suggests that some health professionals who took part in my study challenged, through their practices, the dominant construction of sexuality, in which ‘real’ sex is positioned as vagina/penis intercourse (McPhillips et al., 2001).

Post-cancer bodily changes and changes to gendered identity.

In addition to recognising the impact of post-cancer changes to the sexual organs on sexual practices, it was also acknowledged by participants that changes to gendered identity could be experienced. For example, a few participants also talked about how masculine identity could be “diminished” following men’s experiences of
the loss of sexual performance, including David, a bereavement counsellor, who reported that:

With the loss of erection, the loss of potency, men often feel somehow diminished. Their sexual functioning is diminished. Their masculinity is diminished because their ability to be able to perform is caught up in their sense of being a man.

Similarly, Ian, a nurse, spoke about a male palliative cancer patient whose loss of sexual desire had negatively impacted his sexual identity and sexual relationship:

His energy levels are a half of what they were before, and his desire, his senses, is just gone. Like it’s just gone. Like he just doesn’t feel desire anymore. And this was a real big problem for his sexuality, his identity, and because sex was a big part of his relationship.

These accounts accord with previous research, in which men have reported that these post-cancer changes to their sexual functioning often contribute to the loss or diminishment of their masculinity. This occurs because the loss of sexual performance is diametrically opposed to phallocentric hegemonic constructions of masculinity, which position ‘real men’ as those who ‘want’ sex, and are able to ‘do’ sex with ease (Arrington, 2003; Fergus et al., 2002; Gilbert et al., 2013; Tiefer, 1994; Ussher, Perz, & Gilbert, 2015).

The impact of post-cancer bodily changes on the gendered identity of women was also discussed by participants. For example, the account of David, a bereavement counsellor, highlights that the loss of reproductive organs can affect the gendered identity of women who have cancer:

I remember working with a woman who had a double mastectomy, and she talked about the scarring and the impact of that, whether she’d be attractive. But
yeah, she felt a loss of womanhood [following the double mastectomy]. And I also remember speaking to a woman who had had a hysterectomy [to remove cancer]. She described it as “the loss of my castle”, because that’s the place where her four daughters were born.

The reproductive organs, including the breasts, are positioned as symbols of motherhood, femininity and female sexuality (Ussher, 1996). Accordingly, women with cancer who undergo physical changes to, or the removal of reproductive organs or other forms of infertility, often experience and report diminished identities of femininity and motherhood (Gilbert et al., 2010b, 2011; Greil et al., 2010). As David’s account illustrates, physical changes to or the loss of a breast - a visible signifier of feminine sexuality – can lead to feelings of sexual unattractiveness (Berterö & Chamberlain Wilmoth, 2007), and loss of femininity (Manderson & Stirling, 2007), with previous research indicating that women who experience mastectomies experiencing greater body image problems than woman who have had reconstructive or breast conserving surgery (Fobair et al., 2006). David’s account also highlighted the loss of “womanhood” that can be experienced following removal of the uterus, which can occur irrespective of whether the woman has borne children or not. This has been confirmed in previous research, which found that women, including those who have had children, who constructed their femininity as being linked to their ability to bear children, experienced greater loss, diminished body image and lower self-esteem following the removal of their uterus (Juraskova et al., 2003).

Other participant accounts also described how women’s gendered identity could be disrupted post-cancer. For example, Kay, a counsellor, questions, “a woman patient, does she feel like a woman anymore, now that her entire body has been
through so many dramatic changes, is in pain, and has issues of deformity?” This is in line with previous research which has demonstrated that men and women can experience changes to their gendered identity after cancer, irrespective of whether they have experienced changes to their sexual organs (Gilbert et al., 2012; Parton, 2014). For example, the experience of post-cancer bodily changes that is also associated with aging, such as increased pain, fatigue, decreased sexual desire and physical mobility, have led some women to liken their bodies to older women’s bodies. Accordingly, drawing on constructions of aging and asexuality, these women positioned their bodies as unattractive, and outside normative constructions of idealised femininity (Parton et al., 2015). Similarly, for women with cancer, it was noted by participants in my study that changes to the skin could make women feel unattractive, with many endeavouring to conceal these changes. For example, Jennifer, a palliative care physician, observed:

Some women with breast cancer get dreadful skin disease, particularly on their chest, which might make them feel, they don’t want to be seen sort of in a sexual way. Some of the very nasty cutaneous breast cancers can make women feel they just don’t want anyone to see them, not even their husband.

Feminine beauty is represented by young skin that is free from flaws (Bordo, 2003). Consequently, as Jennifer observed, women who experience skin changes such as “cutaneous breast cancers”, can position themselves as unattractive within idealised constructions of feminine beauty, and as a result, may wish to conceal their bodies in an effort to contain the abject and unfeminine body, as has been reported in previous research (Parton, 2014).

Additionally, a number of participants identified that women who had experienced changes to their physical appearance may feel sexually undesirable and
uncomfortable ‘revealing’ themselves to their male partners. For instance, Helen, a nurse, said, “I can’t even imagine what it would be like to be quite disfigured from your cancer and then to be able to respond to your husband and be confident in that. I would find that very, very difficult”. Likewise, David, a bereavement counsellor, recalls a male client who spoke of his wife’s withdrawal from sexual contact following her mastectomy, explaining that whilst emotional connection was maintained through shared activities, his wife kept her body concealed from him, and all physical contact between them ceased:

I can think of one man who talked about his wife who was diagnosed with breast cancer, and she eventually died quite a few years later. But from that time that she was diagnosed she didn’t want him to have any physical contact with him at all. Ah, she wanted him to sleep in another room. Particularly when the mastectomy had occurred, she didn’t want him to see her naked at all, and in fact he never did again until the very last days of her dying in the hospital when he had to support her, help with her dressing. But he never ever did see the wound, or see her without clothing on. And she didn’t like or want him touching her, ah, so for him that was an enormous experience of loss and grief. Though he did talk about other aspects in which intimacy was expressed in the relationship… but that intimacy appeared to have significantly changed from a more physical based intimacy to a more intimacy based around shared experiences.

This confirms previous research that has found that the loss of a feminine body can contribute to some heterosexual women feeling as though they are not sexually desirable to their male partners, or to other men. That is to say, they became ‘invisible’ within the male gaze (Parton et al., 2015; Ussher et al., 2014). However, it
is also noteworthy to point out that health professionals did not report that heterosexual men may also find it “difficult”, and lack confidence, with exposing their changed physical appearance to female partners. This discrepancy likely reflects the dominant binary construction of women and men in Western cultures, where women are positioned as sexual objects within the male gaze, “as instruments for the sexual servicing and pleasure of men” (Calogero, Tantleff-Dunn, & Thompson, 2011, p. 4), whilst men are positioned as non-reciprocating sexual subjects (Bartky, 1990). Thus, health professionals may be positioning heterosexual women as more likely to report or experience concerns about how their changed physical appearance affects their male partners, than heterosexual men. Given that women’s lifetime exposure to sexually objectifying experiences changes their self-body relations, so that women also come to view themselves as “objects, to be looked at and evaluated from the outside” (Calogero et al., 2011, p. 8), it may be that heterosexual women are more likely to experience or report concerns about how their changed physical appearance affects their perceived desirability with men. Indeed, there is existing cancer research which appears to support that people with cancer also construct their sexuality through a subject/object binary construction. In particular, this research has demonstrated that heterosexual women tend to report changed body image, and the perceptions of embodied change by others, as a primary concern, whereas men are most likely to report concerns about loss of sexual performance, and the subsequent impact this has on their masculine identity, as a primary concern (Gilbert et al., 2012; Ussher et al., 2014). Therefore, future research conducted with people with cancer could examine whether there are gendered differences in whether heterosexual men or women experience concerns about ‘revealing’ their changed physical appearance to their partners. Likewise, future
research could also explore whether health professionals are more likely to perceive that sexual attractiveness is a greater issue for women, rather than men.

Lastly in relation to post-cancer changes to gendered identity, health professionals identified times when people with cancer resisted further ‘life-saving’ or ‘life-prolonging’ treatment, to avoid the threat of further changes to their gendered identity. As Matthew, a psychologist, recounts:

I worked with a woman and she had metastatic breast cancer. And she’d gone through chemo multiple times and lost her hair and it had grown back, and they said, “well, look, your cancer’s advancing, we can try one more chemo, we’re not sure if it’s going to work”. And she was very much like, “well am I going to lose my hair?” And they said, “well yes you are”. And she’s like, “well I’m not going to have it”. And I view that as a way of, this kind of sense of being a woman and sense of her identity.

This account demonstrates that gendered identity is important for many patients, as has been reported in previous research (Gilbert et al., 2012; Ussher, Perz, & Gilbert, 2015). Moreover, this account also indicates that preserving gendered identity can be an important consideration for people with cancer who are considering further cancer and life-prolonging treatments, though future research could further investigate how patients’ cancer treatment decision making may be impacted by their wish to preserve their gendered identity or their physical sexual wellbeing.

In sum, the accounts that health professionals provided within this theme showed that they were aware of how bodily changes impacted upon the sexual practices and gendered identities of people with cancer, and the corresponding impact this could have on their intimate relationships. They also provided accounts of the support they provided in response to these changes, which included: providing
information about non-coital forms of expressing sexuality; assisting couples to verbally negotiate the amount and type of sexual contact that occurred; and providing opportunity for empathic listening and acknowledgement of the distress these changes caused people with cancer or their partners. I will now move on to discuss the health professionals’ awareness of the impact that advancing bodily deterioration - which is frequently associated with end-stage disease - had on people with cancer and their partners.

“People feel very undignified”: Advancing bodily deterioration - Loss of bodily control, increased care needs and ‘dirty dying’.

Health professionals I interviewed recognised that for some patients the increasing loss of control over their bodily functions often meant that patients had to rely on others for “intimate” body care and support. With this, it was acknowledged that the loss of control over bodily functions potentially seriously threatened the dignity and selfhood of people with cancer (Waskul & van der Riet, 2002), as the account of Maureen, a social worker, illustrates:

Well how’s a man, who’s been an active, independent man, who’s now being showered and wearing a nappy feel? And women do to. But generally people feel very undignified like that, and lose their dignity and that’s really, really hard. It’s really hard to be naked and some stranger showering you.

Similarly, Veronica, a social worker, likens the dependency needs of end-stage patients to that which is required by infants, qualifying that “even” babies may be more independent than end-of-life patients:

I often talk about, I mean, when people are actually in their last days, you’re doing such intimate care, such as wetting their mouth, and spraying water into their mouth and putting ice cubes into their mouth. It’s so intimate. It’s like a little baby really. In fact, even more so, I mean, babies can even do that.
These accounts illustrate that the loss of independence that end-of-life patients may experience can reduce them to an “infantile ‘non-person’ status” (Waskul & van der Riet, 2002, p. 499). As Maureen’s account illustrates, this is often a profoundly difficult experience for patients, with many reporting feelings of powerlessness, helplessness and humiliation (Waskul & van der Riet, 2002). Likewise, participants noted that witnessing bodily deterioration, and taking up an increased role in caring for the person with cancer, was often a difficult experience for partners. For example, Jennifer, a palliative care physician, reports that due to the demands of the caring role, a couple’s relationship can often move to a “functional, physical” relationship, rather than an intimate relationship:

> I think often partners end up being nurses for them, certainly near the end of life. They change stoma bags or wipe their bottoms or lift them onto toilets or wash them and it becomes a very functional, physical relationship rather than a romantic one, and I think partners can really struggle with that, and they may feel guilt around that.

Likewise, Veronica, a social worker, also details the care practices that partners may perform:

> I think with palliative care and cancer care…it’s the physical impact of the illness on the body, can lead to a whole lot of intimacy needs between the couple that they would never have journeyed into that before, such as bowel care, and urinary incontinence, or vomiting and hair loss. Those issues around being the person that you weren’t and being able to be in that space with the other person.

In both accounts, health professionals made reference to caring practices, such as “wipe their bottoms…wash them” and “urinary incontinence”, that would also be
carried out between parent and their child. These accounts illustrate the repositioning of patients within intimate relationships that can occur through increasing bodily deterioration and care needs, with patients becoming viewed as ‘childlike’ or ‘asexual’ sick patients by their partners, as has been reported in previous research (Gilbert et al., 2009; Hawkins et al., 2009; Taylor, 2015). Accordingly, diminishing sexual contact between couples is often experienced, because the transitioning of the patient to an ‘infantile’ status, and the type of care that is necessitated by this transition, is antithetical to Western social constructions of adult sexual relationships (Gilbert et al., 2009).

Health professionals I interviewed responded to this issue by empathising with the distress of patients and carers and by focusing on strengthening and affirming other positive aspects of the couples’ relationship. As Janine, a social worker, illustrates:

It’s just so painful, so painful and it’s such a burden for each of them that I watch the various ways people try and protect each other from it and I talk to people quite openly about that and try and make them see how much they’re loving each other and how - how much they’re trying to protect each other. That’s - that’s a big part of the work I’m doing to try and facilitate their appreciation of each other’s care and love and people do that in just so many different ways.

This approach is consistent with the suggestions of previous researchers, who have suggested that health professionals can assist couples by empowering them to openly discuss these issues together, and by offering emotional support to both parties (Gilbert, Ussher, & Perz, 2010a).
In addition to noting the difficulties that people with cancer and partners face with the patient’s increased needs for physical care, health professionals also described the profound impact that advanced bodily deterioration, particularly in the latter stages of terminal illness, had on the person with cancer. For some people with cancer, the bodily changes they experienced could not be hidden or ‘remade’. These included, “smells, and stomas, having stomas that fall off…certainly does come between a patient and being able to manage closeness with somebody” (Jean, a nurse), and “fungating smelling masses” (Matthew, a psychologist). Julia Lawton (2000), who examined the dying process, argued that some people with terminal illness reached a stage in their illness where their bodies became ‘unbounded’. Here, Lawton used this term to refer to “…the literal erosion of the patient’s physical boundaries” (p. 128), a stage in which patients often required symptom control for incontinence, uncontrolled vomiting, fungating tumours, and weeping limbs caused by oedemas. Lawton noted that despite being treated for these symptoms, the condition of some patients worsened to a point where their bodies could not be ‘rebounced’, and these patients were most likely to remain at the hospice until they died. At this stage, Lawton witnessed that many people with cancer appeared to experience an extreme loss of self, and responded by ‘switching off’ and becoming ‘disengaged’, a process she described as a form of ‘social death’.

Health professionals in my study also observed this phenomenon in some patients, and described the withdrawal of patients not only from sexual and intimate contact, but from all social contact. Karen, a nurse, explains, “you become more and more introverted as things change and you get sicker and sicker and sicker. You lose all the things that you are able to do. You disconnect from all those things”, and, Carla, a social worker, explains, “at this very end stage of life, they’re
usually coming in ‘cause their symptoms are quite bad, and I think this starts the process of them starting to withdraw socially too. So I imagine that their sexual life is as well”. Finally, Kelly, a nurse, also explains patient withdrawal following severe illness, and also describes the impact this withdrawal has on their partner and relatives:

> When patients are really sick, they’re close to dying, they really do withdraw into themselves. And I find that’s a really tough time for relatives. They really start to withdraw from life, and I think that must be just an incredibly difficult time for partners because they really go from sort of interacting a little bit and needing them for things…you know that washing part could be the last of their physical, intimate relationship…and they go from just being full-nursing care and then they go into the hospice. Well, they’re just shutting down. Their bodies are shutting down…they’re too sick to interact anymore and they spend more time sleeping and less time awake. They really just don’t want to [interact] – like, they’re not really living anymore.

Lawton (2000) argued that this withdrawal from the ‘outside world’ was akin to the withdrawal, caused by overwhelming physical and emotional helplessness and despair, which was observed in some holocaust survivors. Likewise, she argued that some palliative patients experienced a self “imposed social death” (p. 132), which emerged from a similar experience of helplessness and emotional and physical trauma that resulted from having an ‘unbounded’ body which could not be ‘rebound’. Further, Lawton also noted that the hospice “served on one level as a ‘fringe/liminal’ space, within which these ‘non-persons’, wavering between two worlds, remain buffered.” (p. 133). In other words, the hospice becomes a place of containment for patients who occupied ‘unbounded bodies’, which, no longer able to be ‘self-
contained’; are cloistered from ‘public’ spaces. Thus, these observations that people with ‘unbounded’ bodies often experience extreme loss of self and disengagement from social interactions, points to the importance, at least in Western culture, of having a bounded body, as this body is “central and fundamental to selfhood” (Lawton, 2000, p. 133). Correspondingly, having a bounded body also appears central to an individual being able to experience and express sexuality, given that sexuality is inextricably linked to a person’s sense of self. Therefore, these accounts illustrate that advanced bodily deterioration, in particular deterioration that advances to a stage when the body cannot be ‘rebound’, can have a profound impact on the person with cancer and their partner, something which was evident in my participant accounts.

I will now turn to discuss the final issue in this chapter, which are the experiences of health professionals who have responded to sexual violence in the palliative setting.

**Responding to Sexual Violence in the Palliative Setting: The Experiences of Health Professionals**

A number of health professionals I interviewed described times when they had worked with palliative patients who they felt were at risk of experiencing, or who had experienced, sexual violence, perpetrated by their partners. Participants explained that some cases were challenging to respond to, as due to the patient's physical or functional deterioration, it was difficult for them to ascertain whether the patient would have provided consent to their partner for sexual contact. As such, these cases caused discomfort for health professionals, who said they were unsure how to best support the patient and make decisions on their behalf, such as arranging
guardianships, which would ensure their safety. This is an issue that Dianne, a social worker, spoke about:

The only time I feel emotional is if it’s a patient that I don’t believe is well enough to give their [sexual] consent anymore. That makes me very uncomfortable - that makes me really uncomfortable. And I’ve had to address that, um, you know, whether we need to do guardianships or – and those things. And that, I find very confronting, because it makes – that’s the only emotion I really feel in that situation, when I think that they’re – that it’s really an abuse situation, rather than a, um, couples meeting.

Interviewer: Could you tell me about a situation like that?

Yeah. A young woman with a brain tumour, who is no longer verbal and no longer able to care for herself. And the husband wants them to go home for day visits, from they’re – they’re in a nursing home, and her husband wants her to go home for day visits and it’s assumed that it’s a conjugal. And she, you know, there is no way she can give consent because of her physical condition and she is at risk being moved. And she may be at risk participating. But that’s been difficult. And, before we had to confront it, nature took its course so we didn’t actually have to make a decision on it, but yeah. And, you know, it is difficult, because, she may have, if she was able to give consent, she may have given consent, you know. So it’s – it’s tricky.

In addition to highlighting how difficult it can be for health professionals’ to identify whether a non-verbal patient has been able to provide sexual consent, Dianne’s account also draws attention to the complex issue of sexual consent and rape in relationships that health professionals need to be aware of, and which they may need to negotiate, during their practice. There are several normative cultural discourses of
sexuality, gender, and relationships that may work together to shape a person’s understanding and experience of sexual consent and sexual coercion. Firstly, sex is commonly constructed in Western cultures as a ‘normal’, ‘healthy’ and necessary component of ‘loving’ relationships. Accordingly, unwanted sex may not necessarily be construed as rape by partners, including those in heterosexual and same-sex relationships, who may participate in sex because it is perceived as a central component of a normal, loving relationship, and a demonstration of their care for their partner (Budge, Keller, & Sherry, 2015; Hayfield & Clarke, 2012b; McPhillips et al., 2001; O'Sullivan & Allgeier, 1998). The centrality of sex as an ‘essential’ component of a ‘normal’ relationship may also be used by one partner to justify their sexual coercion of the other partner, as has been found in other research (Budge et al., 2015; McPhillips et al., 2001). Secondly, the hegemonic discourse of male sexuality which constructs men as having greater sexual desire and sexual agency than women – which has been termed the male sexual drive discourse (Hollway, 1984a) - can also work to normalise and justify sexual coercion and unwanted sex (Gavey, 2005; Ussher, 1997). For example, it has been recognised that some women in heterosexual relationships may not position their engagement in unwanted sex with their male partners as oppressive or the result of coercive practices, if they position themselves as responsible for meeting their male partner’s sexual needs (Hayfield & Clarke, 2012b; Hyde, 2007). Likewise, given this male sexual drive discourse, some men themselves may feel a level of entitlement to having their sexual needs met by their female partners, and may not consider their unwanted sexual advances as sexual coercion or rape, or may use this discourse to justify sexually coercive practices and rape (Gavey, 2005). Further, it has also been found that the male sexual drive discourse, rather than particular aspects of gay cultures, is
central in allowing some gay or bisexual men to employ and normalise sexually coercive practices against other men (Braun, Terry, Gavey, & Fenaughty, 2009).

Lastly, unwanted or forced sex may occur in intimate relationships, and not be considered by the perpetrator as rape, due to their adoption of the notion that once someone has consented to sex within a relationship, they have irrevocably consented to sex for the remainder of the relationship (Martin et al., 2007). These examples illustrate that it may be hard for health professionals to identify situations where patients or partners perceive that their sexual consent has not been given, and accordingly more difficult for health professionals to respond to sexual coercion in palliative settings. The above discussion also demonstrates the importance of health professionals having an awareness of how normative discourses around masculine sexuality, ‘healthy’ relationships and gender roles provide cultural scaffolding for sexual coercion and rape to occur, and shape the experiences and sexual relationships of patients and partners. Having an awareness of these discourses may also enable health professionals to help patients and partners identify sexually coercive practices that may be occurring in their relationship, and, if safe, assist them to challenge or resist their engagement in unwanted sex, or perhaps re-negotiate their sexual relationship.

Other health professionals spoke about working with patients where sexual violence had clearly occurred. For example, Pamela, a social worker, spoke about a female palliative patient who had reported to a member of the community health professional team that her husband, who was providing medical care for her at home, had “raped her”. Although the health professionals involved in this case acknowledged that the sexual assault had occurred, and was likely ongoing, they were unable to implement alternative care arrangements that would ensure her safety.
This was because the female patient wished to “die at home”, which meant that she needed to continue to rely on the care that her husband provided:

On the darker side of sexuality in palliative care, I was approached when I was fairly new in this job by one of the nurses in the team, and she was working with a woman who was dying, and the woman had formed the belief that her husband, who was her carer, had increased her medication which rendered her unconscious, and during that time had actually raped her. Because when she woke up, you know, it was obvious someone had had sex with her. That was a huge ethical issue, and, we actually made the choice not to do anything about it, in the sense, for the reason that the woman didn’t want to do anything about it because her husband was her sole carer, she was completely dependent on him, and to, you know, raise it as an issue or take any sort of action um, challenge, you know, prejudice the availability of his continued care for her, and she didn’t want that to happen…I guess, I guess my reaction was one of a sense of identifying with the woman who felt really helpless. She didn’t want to be raped, she didn’t want to be rendered unconscious, he was the one who administered her meds and she needed his support. And having a sense of the entrapment that she must have, because there was no way out for her, I mean she could have been admitted to a nursing home or something like that, but she clearly did not want that, she wanted to die at home. So yeah, having a sense of the helplessness of some people, it’s not a good feeling to identify with that.

The above accounts illustrate the sometimes difficult and complex nature of responding to sexual violence in palliative settings, with Pamela’s account, above, in particular demonstrating that health professionals may face ethical dilemmas in
which they are unable to prevent ongoing sexual violence from occurring. It is known that palliative care patients may be more vulnerable and at risk of experiencing sexual violence, as well as other forms of violence, due to the more advanced level of physical and functional deterioration that is often associated with end-stage disease (Culver Wygrant, Bruera, & Hui, 2014). Palliative patients are more at risk because, as Dianne’s account highlighted, due to verbal or cognitive deterioration, they may be unable to communicate their sexual needs, including giving or refusing sexual consent. Further, as Pamela’s account illustrates, patients may not be able to leave abusive relationships due to their dependency on their partner for provision of physical care, or a desire to die at home.

Additionally, a few health professionals also discussed times when partners of palliative patients had disclosed experiences of intimate partner violence, including sexual violence. For example, Carla, a social worker, spoke about a female partner who had disclosed her history of intimate partner violence perpetrated by her husband, and how she (Carla) had assisted in “setting boundaries around his behaviour”, and facilitated discussions which invited him to acknowledge responsibility for his abusive behaviour:

I had quite a lot of involvement with one person who had a history of sexual abuse from her partner who she was now caring for in the end stages of his life. And some of these behaviours continued and just how she managed that and her divulgence of her past history with him of being assaulted and raped in marriage and – and things and just how it was really the first time she’s ever talked about it. So she began to talk about her sexual history with him. So that emerged as a very big part of what she was doing and actually working with him and getting some apology from him then. So it was – ah,
that was very much imbedded in sort of couple therapy side of things. And asking – working with him around setting boundaries around his behaviour in – he’d sort of grab her when she went to give him some breakfast – grab her breasts and grab her, you know stuff that she really didn’t like.

All of the above accounts emphasise the importance of palliative care health professionals recognising signs of intimate partner violence, as suggested as best practice by other authors (O’Doherty et al., 2015; Reisenhofer & Taft, 2013), as well as being aware of the complex issue of sexual consent and rape in relationships, as was discussed above. Other studies have shown that patients who are receiving care in emergency, clinic, palliative and primary care settings want to be screened by physicians and allied health professionals for abusive relationships (Coker et al., 2007; Gremillion & Kanof, 1996; Wright, 2003). As Wright (2003) has pointed out, palliative patients or partners may feel supported and relieved to share their experiences of abuse with health professionals, and health professionals may be able to provide interventions which prevent further violence, as well as referrals for the provision of emotional and other forms of support. In a similar vein, as some palliative patients and partners have anecdotally reported, they may feel empowered to share their experiences of abuse with health professionals, perhaps for the first time, because they know that through their own imminent death, or the death of the perpetrator, there will soon be an end to their abuse (Wright, 2003). Indeed, in Carla’s account, it was reported that the female partner was disclosing the abuse that was occurring in her marriage for the “first time”. It is possible that her decision to disclose the abuse for the first time may have occurred, in part, due to knowledge that her partner was dying of cancer.
Other authors have provided guidelines for how health professionals can identify the presence of intimate partner violence in clinical settings. For example, screening can include looking for signs of psycho-social distress, including observations of fear, or discomfort when being touched during an examination (Mick, 2006). Likewise, health professionals may find signs of intimate partner violence through observing partners who appear overprotective, dominating or controlling during assessment interviews, or who refuse to leave during examinations. Health professionals can also ask direct questions about possible abuse, such as, “are you currently in a relationship where someone is hurting you?” (Culver Wygrant et al., 2014, p. 810), provided the partner and other family members, are not present.

However, it is important to recognise that there are a number of barriers that may prevent cases of intimate partner violence being identified by health professionals. Firstly, individuals who have experienced intimate partner violence may not disclose the abuse for a number of reasons, including emotional distress, fear of escalating or retaliatory violence (Coker et al., 2007), self-blame, or not being aware that their partner’s behaviours are abusive (Mick, 2006). Further, there is also evidence to suggest that patients may not report incidences of intimate partner violence until the second time that they are asked by health professionals, indicating that health professionals may need to provide additional opportunities for patients to discuss these issues (Coker et al., 2007).

Another issue to consider is that many individuals who have experienced intimate partner violence may have never spoken about their experiences, because of the isolation and silencing tactics that are often a feature of this type of abuse. It has been argued that involvement from the palliative care team may assist in breaking
these silencing tactics by revealing the efforts of the perpetrator to ‘conceal’ the abuse, and thus empower the individual to share their experiences (Wright, 2003). It is also worth noting at this point that all of the above accounts provided by participants in my study related to women who were experiencing sexual violence from their male partners. Although intimate partner violence can be experienced by anyone, regardless of gender, class, cultural background, or sexual orientation, it is well known that intimate partner violence disproportionately affects women, and is most often perpetrated by male partners (Australian Bureau of Statistics, 1996; Krug, Mercy, Dahlberg, & Zwi, 2002). With this, it is known that women who experience physical or sexual violence are also more likely to experience emotional abuse - including isolation, intimidation and manipulation (Australian Bureau of Statistics, 1996). It is, therefore, important that health professionals are aware that the forms of violence and the coercive controlling strategies that women experience often present differently to that which is experienced by men. Such knowledge can assist in the screening and identification of these forms of intimate partner violence.

Finally, the older age of many palliative patients is a factor that may influence the lack of identification or communication around intimate partner violence, for two reasons. Firstly, as Wright (2003) argued, some older women (and men) may not identify their relationship as being abusive, because they have not been exposed to the increased public attention towards partner violence, and the campaigns to establish domestic violence support services, spurred by the feminist movement in the 1980s and 1990s. Lastly, the older age of most palliative patients might also be a factor in health professionals neglecting to screen for sexual violence. Health professionals may overlook screening for sexual violence with many couples using palliative services because of the pervasive socio-cultural myth that older people are
not interested in, or no longer practice, sex. Indeed, there is abundant evidence which has shown that many health professionals, including participants in my study, neglect raising issues of sexuality with older people due to adopting this discursive construction that older age and sexuality are mutually exclusive (Bradway & Beard, 2015; Hordern & Street, 2007c; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013), which is an issue which will be explored in the next chapter.

In conclusion, it is clear that many of the health professionals in this study acknowledged the need to identify and respond to sexual and other forms of intimate partner violence in palliative settings. However, these accounts, in line with previous research (Culver Wygrant et al., 2014; Gremillion & Kanof, 1996), also illustrate that recognising and responding to sexual violence can be difficult, as well as distressing for health professionals, who may be faced with situations where there is no clear way to prevent the ongoing occurrence of such violence, and who may identify with the distress that the victim is experiencing. Thus, whilst others have provided suggestions for identifying and responding to intimate partner violence within clinical settings (Culver Wygrant et al., 2014; Gioiella et al., 2008), it appears important that health professionals be able to receive supervision, so that they have opportunity to discuss difficult cases, as well as seek support for any emotional distress that they may experience.

**Conclusion**

Overall, the participants in this study demonstrated a broad understanding of how cancer and palliative illness could impact the sexual wellbeing and sexual relationships of palliative patients and their partners. In line with reports from palliative patients and partners (Lemieux et al., 2004; Taylor, 2014), the participants recognised that palliative patients and partners may experience a renewed sense of
intimacy and a strengthening of their relationship in the palliative phase of their illness.

Participants also acknowledged that physical post-cancer changes to the patient’s body could place palliative patients outside of normative discourses of functioning, femininity and masculinity, thus often leading to detrimental impacts on the sexual wellbeing and relationships of palliative patients and their partners. This included recognition that due to the distress caused by the patients’ abject bodily changes, either the patient or the partner may withdraw not only from their sexual relationship, but also from the relationship itself; as has been found in previous research (Manderson, 2005; Taylor, 2014; Ussher, Perz, & Gilbert, 2015). The participants also recognised that patients or the partner may withdraw from the relationship due to the experience of anticipatory grief, an issue that palliative patients have reported in recent research (Taylor, 2014). Participants in my study also acknowledged that palliative patients and couples may not be able to engage in the same sexual practices as they may have done before their illness, with difficulty with coital sex cited as a common concern for patients. These findings therefore align with the reports of palliative patients and partners from previous research, where many have reported high levels of sexual dysfunction, and high levels of emotional distress as a result of these changes (Ananth et al., 2003; McClelland et al., 2015; Vitrano et al., 2011).

Finally, the issue of how health professionals may negotiate and respond to issues of sexual consent and violence has not previously been empirically examined in relation to the context of palliative care. As such, this study has added to the current literature by identifying that palliative care health professionals have to negotiate the discourses around sexuality, gender and relationships that can create a
cultural framework for sexual coercion and rape to occur (Gavey, 2005), as well as the material impacts of advanced cancer which can make patients more vulnerable to sexual violence (Culver Wygrant et al., 2014).

Along with demonstrating knowledge of how cancer and palliative illness impacted the sexual wellbeing and relationships of their patients and partners, it was found that many participants also responded to these sexual and intimate concerns. In particular, many participants reported that they endeavoured to strengthen and enhance their patient’s relationships by encouraging non-sexual physical expressions of intimacy. They also reported that they responded by providing emotional support, and by facilitating couple communication – the latter reportedly being effective in reducing self-silencing practices between couples, in improving emotional and physical intimacy, and in assisting couples to engage in emotion work. As such, these findings support previous research which has demonstrated that couple-based interventions, where couple communication and the discussion of post-cancer sexual changes is emphasised, can reduce couple distress (Scott et al., 2004; Ussher et al., 2009), reduce self-silencing practices, and also support relational intimacy (Dieperink et al., 2015; Perz et al., 2015). These findings also address the call for research to explore how palliative care health professionals can “facilitate connecting between partners” (Taylor, 2014, p. 445).

Further, it is important to draw attention to the finding that in the present study, both medical and non-medically trained health professionals positioned strengthening their patient’s intimate relationships and encouraging non-sexual intimate touch as an important part of their professional role. This is because these findings stand in contrast to other research which found that medically-trained health professionals predominantly recognised and addressed the ‘medical’ aspects of
sexuality - such as how sexual functioning and fertility is impacted post-cancer - rather than the psycho-social aspects of sexuality (Forbat et al., 2011; Hordern & Street, 2007a). One explanation for this discrepancy in research findings may be that palliative health professionals construct the sexual and intimate needs of palliative patients differently to those of non-palliative patients. Specifically, a core tenet and goal of palliative care is assisting patients to die with dignity, which involves preserving quality of life and helping patients to ‘achieve’ a good death (Chochinov, 2002). To this end, strengthening relationships and assisting patients to maintain hope and meaning in life has been recognised in the palliative care literature as key components in achieving a ‘good death’ (Little & Sayers, 2004). Thus, within this palliative care paradigm, participants may have likewise prioritised the importance of relationships and intimacy in helping patients to achieve a ‘good’ death, and in reconstructing hope and meaning in the face of the losses that death brings (Chochinov, 2006; Little & Sayers, 2004). However, the discrepancy in research findings may also reflect that health professionals in my study self-selected to participate, and had an average of 12 years of palliative care experience. Thus the participants may have been more confident and experienced in addressing these sexual and relational concerns comparative to other palliative care health professionals in Australia.

Lastly, whilst some participants in my study reported giving patients and couples information about alternative, non-penetrative sexual practices – information which reportedly improved sexual relationships and assisted patients to make decisions about further cancer treatment - these reports were in the minority. The participants’ reported difficulty to talk about concerns relating to sexual practices is an issue which will be explored over the next two chapters. However, it is pertinent
to note here that the lack of communication about alternative sexual practices is a problematic issue, given a large number of advanced cancer patients have reported wanting to receive this information from health professionals due to penetrative sex being difficult or undesired (McClelland et al., 2015).

In sum, this chapter addressed how participants identified and responded to a variety of physical, psychological and relational changes that impacted the sexual wellbeing and relationships of palliative patients and partners. However, in the present study it was also found that many participants experienced challenges to recognising and responding to some sexual and intimate concerns. These challenges will be detailed and explored over the next two analysis chapters; beginning with the next chapter which will examine the discursive person-centred barriers that health professionals experienced.
Chapter Five: The Discursive Patient-centred Barriers to Health Professionals’

Recognising and Communicating about Sex

In this chapter I will discuss the ways in which the accounts of health professionals were shaped by socio-cultural constructions of dying, illness, aging, culture and sexuality: constructions that appeared to contribute to normative assumptions about the sexuality of people with cancer and their partners. When health professionals drew on these constructions, some people with cancer were positioned as “not needing to know” about issues of sexuality and intimacy, which meant that health professionals were excused from addressing, or even considering, the sexual and intimate concerns of both people with cancer and their partners.

Not all palliative care recipients consider sexuality to be an important aspect of their lives. However, if patients are positioned by health professionals as “not needing to know” about sexuality, then these issues will simply not be raised, or even considered, by health professionals or other care staff. The effect is that many people with cancer, including those who still have sexual needs or desires, fail to receive information about changes to their sexuality, sexual relationships, and alternative sexual practices. This stands in contrast to health care professionals’ positioning of sexuality and intimacy as a “fundamental” and “core” component of a person’s sense of self and quality of life, the latter being particularly important in assisting people with cancer to cope and adjust to the often very real and material effects of living with cancer and a terminal illness.

In this chapter I will outline and discuss the three key cultural constructions that functioned to limit health professionals from addressing sexuality and intimacy. The first was the cultural construction that some people with cancer are ‘too old’ for sexuality. This cultural construction of age and sexuality meant that older people
with cancer were firstly positioned as asexual and uninterested in sex; and secondly that they would be offended by discussions of sexuality. The second construction was the view that palliative care patients would be focussed on “surviving” their illness and medical treatments, rather than prioritising sexuality. The third construction positioned advanced cancer patients as ‘too ill’ to engage in sexual practices, with ‘dying’ positioned as diametrically opposed to sex. The final construction made about patients stemmed from the dominant heterocentric biomedical discourse of sexuality, which led health professionals to overlook the sexual and intimate needs of single, widowed or same-sex patients, and dichotomised the sexual needs of patients based on their gender.

‘Sexuality is For the Young, and Not the Old’: Positioning Sex as Irrelevant and Taboo to Discuss with Older Age Groups

‘Older patients are not interested in sex’.

A frequent barrier to health care professionals’ raising issues of sexuality was that some patients were positioned as “old”, and, thus, as asexual. This positioning of older people as asexual draws from a popular and dominant socio-cultural discourse that sexuality is only for the young and able-bodied (Hinchliff & Gott, 2011; Shildrick, 2005) - (re)creating the cultural construction that older people are non-sexual beings (Bevan & Thompson, 2003; McAuliffe et al., 2007; Thompson, 1995) who, as they age, are less interested in sexual and intimate issues and in maintaining sexual activity (Bradway & Beard, 2015; Hordern & Currow, 2003). Accordingly, most of the health professionals in this study reported that whilst they would discuss issues of intimacy, such as relationships and physical touch, they would “very rarely” raise or discuss issues of “sexual expression” with ‘older’ palliative patients, who were often defined by health professionals as being over the age of 50. For example,
Maureen, a social worker, aged 59, also notes that issues of “sexual expression”, including “sexual intercourse”, are not often discussed with older people due to their age, and that when they are discussed, it is often in the context of physical expressions of intimacy, such as touch and sharing a bed, rather than “sexual intercourse”:

When it comes to sexual expression, that doesn’t come up very often, maybe because a lot of people have aged … it’s not a priority for people… like if married couples, it sort of comes up in the sense of, ‘oh, he’d got to have a hospital bed now, so we’re not sleeping together and that’s been supporting’. So they’re sharing, they might have been sharing that bed for 30, 40, 50 years and occasionally I hear a comment, ‘oh that’s disappointing’ or ‘that’s really sad’, or that’s another letting go – it’s often they’re saying things like that, but when it comes to sexual intercourse or things like that, it’s rarely talked about.

Similarly, Janine, a social worker, aged 59, reports that although she considers intimacy to be an important issue to discuss with “all” palliative care recipients, she finds that “sexual expression” is “hardly ever” discussed in her setting because older people dominate the palliative care sector:

We talk about relationships and relating and all the aspects of intimacy, whereas not sexual expression, uh, not much um, on genital sexual um, expression – that very, very rarely comes up. Very rarely. I hardly ever, particularly with older couples. Younger couples we might go into that terrain on – about the impact of illness….yeah, but then the older people we work with in our populations are mainly elderly.
Janine’s use of the qualifiers “particularly” and “might” is important to note. Discussions of sexuality do not occur, “particularly with older couples”, given the positioning of older people as outside the boundaries of sexuality. But even with younger couples, discussions of sexuality are only a “might”, which may reflect a broader cultural discourse that sex is a taboo and private subject which should not be discussed regardless of age (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Yet what must be considered here is that if health professionals draw on both cultural constructions - that is, that sex is private and that older people are asexual - then clearly, discussions of sex with older people are even more likely to be positioned as irrelevant, and therefore less likely to occur.

In some of the accounts, health professionals challenged the cultural construction that sexuality was not important to older people, and that older people did not engage in sexual expression. However, at the same time they also stressed that these cultural constructions of aging and sexuality were difficult to overcome and thus continued to seep into their practice, creating discomfort and difficulty in their attempts at raising sexuality with older patients. For example, Jenny, a palliative care specialist, aged 39, explained that the “assumption” that older people were not sexual or interested in sexuality was “wrong”, but, she pointed out that this assumption pervaded her own practice and made her reluctant to raise discussions of sex with older patients/couples:

Definitely younger people, I find it easier to raise (sex) with them than elderly people. And I know that’s an assumption that lots of people make, that elderly people wouldn’t be sexually active, and I know that’s wrong, and I still find it really hard to raise with them (laughs)…you know, they might
say, “Oh, I know that my body’s not the same anymore”, and I would just empathise with that rather than saying, “does that make sex difficult?”

Similarly, Fiona, a nurse, aged 49, conveyed her reluctance to raise sexuality with older people, stating, that, “I understand that intimacy and sexuality is just as important to older people but yeah, I’d be more inclined to bring the subject up to a younger person”. Ian, another nurse, aged 49, also expressed his discomfort around discussing issues of sexuality with older people, and in particular, discussing the use of sexual aids:

It’s about getting over the discomfort of talking about, you know, perhaps using sex aids…but also then talking to, especially an older person, about using these sorts of devices, you know, vibrators or uh, gels or whatever, or even just parts of the body…we kind of tend to think of other ways of having sex as being more of a younger person’s thing…I tend not to really want to think about an older person having oral sex or anal sex or whatever, so really that’s a big barrier I feel…and I really think on the whole we tend to think (whispers) older people, they just can’t possibly do that sort of thing, they don’t do sex anymore do they!? (laughs) But they do!

In Ian’s account, he explains that talking about “even just parts of the body” causes him discomfort. Arguably, the assumption here may be that one cannot even think of an older body, let alone render it as sexual. By posing the question, “if society is hesitant to view the aging body, how can we imagine sexual relationships of seniors?” Watters and Boyd (2009, p. 309) have pointed out the problem with older people being represented in such a way. Namely, health professionals - who are part of a society that constructs older bodies as outside of the boundaries of sexuality - will likely, when drawing on this discourse, not be able to “imagine”, or even
consider, the sexual needs of older patients (Hinchliff & Gott, 2011; Shildrick, 2005). In the account above, Ian also explains that “we”, implicating society as a whole, “tend to think of other ways of having sex as being more of a younger person’s thing”, which implies that older people should only have ‘conventional’ sex, namely, sexual intercourse, and that this is the only way “we” can permit ourselves to understand, or even think about, sex amongst older populations. Also evident in Ian’s account is his whispering of the thought that, “older people, they just can’t possibly do that sort of thing, they don’t do sex anymore do they?” This whispering shows how unspeakable it is to accept, or even conceive of the notion, that older people may still be sexually active.

Although most health professionals I interviewed appeared to position older people as not interested in sex, some participants shared incidences of when this positioning was challenged, by older patients who made it clear that they were still sexually active. For example, Dianne, a social worker, aged 59, talks about being “confronted” in her early career by older patients who engaged in sexual activity:

…it’s confronting. I mean, I’m confronted by 90-year-olds that talk actively about their sex life because they’ve got a full on sex life… and you know, to the degree that I stood on guard when somebody has died. I stood on guard while the partner spends time alone, because they want, they feel that they need that last, sort of, time to explore their body… and you think, ‘oh man’, I remember being, as a new grad, I was completely gobsmacked.

Likewise, Matthew, a psychologist, aged 33, recounted his surprise that a 70 year old woman had been concerned about how surgery for colorectal cancer would affect her ability to have sex with her husband:
I was just thinking about a conversation I had with a woman who had colorectal cancer…I think she was going to end up having a bag put on, and she was going to have some surgery that – to take out the tumour it was going to take out a part of her vagina and she was petrified about this, really, really upset about this. And one of the big reasons was that she was very worried about what was going to happen with her husband. And bearing in mind this is a woman in her 70s – and you know, sort of saying “my husband wants sex”. And that was from quite an ethnic background, I think it was Italian.

In this account, Matthew’s use of the phrase, “and bearing in mind”, serves to legitimate his surprise that “a woman in her 70s” would be “very worried” about losing the ability to have sex, by drawing on what he appears to perceive as a shared socio-cultural construction that older people are not interested in sex. Matthew also notes that the woman was from “quite an ethnic background”. The use of the phrase, “quite an”, here implies that some ethnicities are more ‘ethnic’ than others, and that particular ethnic backgrounds would consider sex as perhaps less important, or more taboo to talk about. Indeed, health professionals in other studies have reported feeling concerned about raising sexuality with patients from culturally diverse backgrounds, in case they cause offence (Hordern & Street, 2007c; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). This account highlights how the ethnicity of patients can be an additionally perceived barrier for health professionals to consider raising sexuality with older patients.

Dianne’s and Matthew’s accounts both illustrate, however, that sexuality does remain an important part of the lives of some older cancer patients. Indeed, whilst health professionals may position older patients as asexual or not interested in sex, there is abundant evidence that this view is not shared by older people, including
those receiving palliative care, who report that sexuality continues to remain important to them (Gott, Galena, et al., 2004; Gott & Hinchliff, 2003; Hawkins et al., 2009; Hordern & Street, 2007c; Ussher, Perz, & Parton, 2015; Vitrano et al., 2011). Equally, many older people have reported that whilst sexual functioning and frequency can decline with age and illness, many do remain sexually active and interested in sex (Bradway & Beard, 2015; DeLamater & Sill, 2005; Koch & Mansfield, 2002; Lindau et al., 2007). Further, in other research, older cancer patients have expressed reluctance to raise their sexual concerns due to worry that health professionals will position them as ‘too old’ to be concerned about their post-cancer sexual dysfunction (O’Brien et al., 2011). Therefore, neglecting to address sexuality with older people with cancer is a significant and problematic issue, particularly given that most people receiving palliative care in Australia are in the older age groups, with half (49.5%) of all palliative care recipients over the age of 75, and only 12% aged under 55 (AIHW, 2012). However, despite the abundance of evidence which refutes the cultural construction that older people are inevitably asexual or uninterested in sex, it is apparent from the present study, and others, that this construction of age remains hegemonic in shaping the practice of health professionals, with most health professionals continuing to position discussions about sex with older patients as irrelevant (Hordern & Street, 2007c; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

‘Older patients don’t talk about sex, and would be offended if we raised it’.

Additionally, the cultural construction that older people are not sexual or interested in sex means that older people are excluded from discourses of sexuality, and this contributes to the silence around this issue and (re)creates the social taboo
that older people do not talk about sexuality or would be offended to discuss such issues (Hinchliff & Gott, 2008; Watters & Boyd, 2009). Accordingly, in my interviews, many health professionals reported that they felt trepidation around raising sexual issues with older people with cancer, in case they caused offence and jeopardised their professional relationship and trust with the patients. For example, Julia, a doctor, aged 51, positions sex as a taboo issue to talk about with older people:

“I think that sex for anyone over about 30 is [laughs] taboo generally”. Here, Julia’s account draws attention to a problematic issue, which is, what is actually considered ‘old’? In this instance, Julia positions sex as a taboo issue to talk about with anyone over 30. In another study, health professionals reported reluctance to speak with patients who are similar in age to their own parents (Hordern & Street, 2007b).

Kay, a counsellor, aged 55, also describes her concern about causing offence if she raises issues of sexuality, “you do run the risk when you’re talking to very old people, if you come on very strong asking about sexual intimacy, there could be a risk of offending or horrifying [laughs] actually, a couple of the oldies”. In this account, Kay positions discussing sexuality with older people as not only having the potential to offend, but also the ability to horrify. The other thing to notice here is the use of the word “oldies” to refer to older people. The word “oldies”, as well as the words, “elderly” and “spinster”, which participants in this study also used at times to refer to older people, have been recognised as “patronising and ageist” language (Nussbaum, Pitts, Huber, Krieger, & Ohs, 2005, p. 295) that serves to construct older people as, amongst other things, “religious…sickly…senile, frail, and lacking in energy” (Nussbaum et al., 2005, p. 288). When health professionals employ such language it has two effects. Firstly, it means that health professionals are likely to position older patients as conservative individuals who would be “horrified” by
discussions of sexuality. Thus, by not raising issues of sex with older patients, health professionals are able to position themselves as serving the best interests of older patients (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Secondly, given that sex is commonly positioned within a limiting hegemonic cultural construction of coital sex, and sexual ‘functioning’ as performance (Hyde, 2007; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013), when health professionals use language which constructs older people as “frail” and “lacking in energy”, older people are also positioned as incapable of practicing ‘real’ sex, and thus discussions about sex become irrelevant and unnecessary. This narrow construction of sex as coitus also dismisses other forms of sexual expression that patients and partners are able to engage in post-cancer, and implicitly dismisses those who are not in heterosexual relationships (Brown & Tracy, 2008; Hordern, 2008; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). These findings suggest that it is important for health professionals to be aware of the language they use when thinking or talking about older patients, given the capacity of language to shape sex as irrelevant or taboo to discuss with older patients.

A number of health professionals interviewed also expressed concern that it was not only taboo to raise issues with the “older generation”, but that older patients would be affronted if the subject of sexuality was raised by a “younger person”. This was the case with Kelly, a nurse, aged 44, who said:

I don’t know how much respect they’d have or how comfortable they’d feel about talking about it with a younger person, a generational thing…So I think the barriers for me are, if it’s an older couple, thinking that well, it’s not appropriate as a younger person to ask those questions, if it’s a generational
thing, like, if they're a whole generation older, then is that not talked about?

It’s a bit different to our generation.

Kelly’s concerns may have been misplaced, as de Vocht, Hordern, Notter, and Van de Wiel (2011) found that people with cancer were unconcerned about the age of the health professional who raised issues of sexuality with them. Rather, what is more important is that the person raises and discusses these issues in an authentic manner, where “the professional ‘sees’ the person they are, including their emotional layer and a real life in the world ‘out there’ with everything that comes with it” (p. 615), as opposed to discussing sexuality in a medicalised style. By adopting such an authentic, person-centred approach, de Vocht and colleagues noted that people with cancer would feel more trust towards their health professionals and be more likely to share their “personal issues” (p.615).

Moreover, whilst many health professionals in my study and in other studies (Gott, Hinchliff, et al., 2004; Hordern & Street, 2007c) have reported reluctance in raising sexuality with older people due to fears of causing offence, this stands in contrast with most older people who report wanting opportunities to discuss issues of sexuality with health professionals (de Vocht et al., 2011; Hordern & Street, 2007b). Further, when health professionals adopt a discourse of sex being a taboo issue to discuss with older people, they are also able to legitimise their avoidance of raising sexuality by positioning “themselves as a sensitive health professional simply acting in the best interests of the patient” (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013, p. 1382). Yet, it may be that discussions of sex are also avoided by health professionals because of feelings of embarrassment, or perceiving that they lack adequate skills and knowledge, to respond to what is positioned as such a ‘difficult’ and ‘private’ topic (Haboubi & Lincoln, 2003; Hautamäki et al., 2007; Stead et al.,
2003). Thus, these findings suggest that it would be helpful for health professionals to receive training that will not only encourage them to challenge the discursive construction that older people are asexual or inevitably offended by discussions of sex, but which will also raise awareness regarding how, by positioning older patients in such a way, they are able to legitimise any avoidance of discussing sex with older patients (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

“They’re Sick, What Are You Thinking About?”: Positioning Palliative Care Patients as Focussed on “Surviving” Their Illness

Many health professionals stated that sexuality would not be a priority for palliative care recipients as they assumed the focus of palliative patients would be on “surviving” and “getting through” the treatments for symptom management, the physical symptoms associated with their illness (in particular, pain, nausea and fatigue), and preparing for death, which included the task of “confronting their mortality”. Correspondingly, health professionals cited that the focus of their practice was on “clinical issues”, such as symptom management, organising equipment, and preparing patients to go home. For example, Kay, a counsellor, explains:

We deal with more toward the end of life. And I think energy-wise and symptoms-wise there’s a line that gets crossed toward the end, and I think people [with cancer] go into survival mode and they’re [health professionals] so worried about the patient’s pain, symptoms and literally how many days do you have left...that people [health professionals] think that would be uh, not something that they would worry about so much.

Likewise, Beth, a nurse, explains that, for most health professionals, clinical issues are the focus when people with cancer are unwell:
I think that it’s something that is just…really not recognised because, if you have physical symptoms, often, or things that can be done, nobody [health professionals] would be thinking about those things [sexuality]. They’re sick.

What are you thinking about?

What is worth noting in the above two accounts is that both Kay and Beth use pronouns such as, “we”, “they’re”, and “nobody”. For example, “nobody would be thinking about those things” (Beth). The use of these pronouns serves two purposes. Firstly, it allows for the avoidance of discussing sex, due to patients’ being too “sick”, to be normalised and established as common practice for other health professionals. Secondly, it also enables participants to separate themselves from this practice and thus remove their individual practice from scrutiny.

Further to the above, Madeline, a psychologist, also explains that the focus of care for health professionals is often on clinical issues and preparing patients for death, which creates a barrier to being able to think “globally” about the patient. However, in contrast to the accounts above, she demonstrates reflexivity by acknowledging that she has experienced this barrier in her own practice:

I think probably as well it’s just not seen as a priority, you know, when you’ve got a patient sitting in front of you who’s at the end of their life and confronting their mortality, and they’ve got uncontrolled pain, and up to 20 other different symptoms...I think sexuality and intimacy just in the clinician’s head is probably not even registering on their radar...I think one of the barriers for me, is getting caught up in other stuff and not thinking globally enough about the patient.

Although many health professionals reported focussing on ‘clinical issues’, some health professionals, such as Karen, a nurse, gave examples of how, by being “so
driven by clinical decisions”, sexual issues were often unrecognised to the detriment of the patient’s wellbeing:

I had a conversation with a nurse who – talking about a gentleman she had been out to see, and he’d had to have a catheter inserted and was incredibly upset about this. And we had a conversation at handover and I said, “well had you even considered that this gentleman could still be sexually active? And this was something that was really going to make a huge impact on his life?” And it was not something that had even crossed her mind...we’re so driven by clinical decisions, fixing things up that sometimes other issues are lost along the way.

This focus on clinical management may stem in part from a dominant biomedical discourse that privileges and dichotomises the ‘medical’ and ‘physical’ over the psychosocial, emotional and relational, including sexuality and intimacy. This contributes to staff prioritising ‘medically based’ issues and perhaps not having “non-medical issues” such as sexuality and intimacy, “even registering on their radar”. When health professionals operate within such a framework, their ability to identify and respond to patients’ needs holistically becomes limited, and concerns such as sexuality and intimacy can go unnoticed and unaddressed. This ‘clinical culture’ has been noted by other authors (Hordern & Street, 2007a; Ong, Visser, Lammes, & de Haes, 2000; White et al., 2013), and often results in “mismatched expectations” (Hordern & Street, 2007a, p. 225) between health professionals and patients. Specifically, these studies illustrated that, whilst patients wanted health professionals to address their sexual and intimate concerns in a holistic manner, most health professionals, particularly those who were medically-trained, assumed patients would instead be focused on receiving medical treatments and ‘fighting’ the disease.
To extend upon this issue of the ‘clinical culture’, some palliative health professionals in my study also stated that they assumed people with cancer would have to put their “sex lives” on hold during treatment; and that now they were facing a life-limiting illness, they would not regard sex as an important issue. For example, Maureen, a social worker, explains that people with cancer would put their “sex life” aside until they were “cured”, and that by the time they reached the palliative stage it would no longer be an issue:

I think when people are talking about oncology, people say well, “I’ve got this cancer but I’m going to cure, and I’m hoping to get back to my sex life, I’ll put it on hold”. People get to this stage and it’s not a priority for people.

The supposition that people with cancer would focus on “getting through” their treatments and put their sex life on hold until after their cancer is “cured” has been expressed by health care professionals in previous research (Hordern & Street, 2007b). However, this view does not appear to be shared by many oncology patients, including palliative care recipients, who report that sexuality continues to remain an important part of their quality of life and that they desire the opportunity to discuss issues of sexuality with health care professionals (e.g., Ananth et al., 2003; Lemieux et al., 2004; Taylor, 2014; Ussher, Perz, & Gilbert, 2013; Vitrano et al., 2011). For example, in one of the few quantitative studies examining the sexual needs of palliative cancer care recipients (N=65), 72.8% said that sexuality was ‘very important’ or ‘important’ to their psychological wellbeing, with only 9.1% reporting that it was not at all important. Further, 86.4% of respondents identified that they wanted the opportunity to discuss issues of sexuality with their health care professional (Vitrano et al., 2011). These studies highlight the need for health professionals to be aware of the continued importance sexuality has for many
palliative care patients, and to provide opportunity for palliative care patients to discuss any sexual concerns.

“They’re Getting Used to Changes Over Time”: Positioning Patients as Having Adjusted to Any Sexual Changes Before Reaching Palliative Care

Some health professionals positioned patients as having “adjusted” to any sexual issues earlier in the cancer trajectory; as Dianne, a social worker, illustrates: “I suspect you wouldn’t have that [post-cancer sexual concerns] in palliative care, because they’re, you know, getting used to it over time”. Similarly, Fiona, a nurse, also shares this view, “I think that because a relationship adapts to what happens within it and maybe the relationship had a chance to adapt to a lot of physical stuff happening to one of the people”. This positioning stands in contrast to the findings of Ananth et al., (2003) who examined the impact of cancer on sexual function and found that palliative cancer care recipients experienced significantly more sexual problems than people with early stage cancer, and also reported a lower quality of life, greater emotional distress, and higher levels of sexual dysfunction than people with early stage cancer. Similarly, a more recent quantitative study conducted by Vitrano, Catania and Mercadante (2011) which examined the sexuality of people with advanced cancer, found that many reported a significant decrease in sexual activities and lower levels of sexual satisfaction and effectiveness of sexual activities, than their pre-cancer experience. Specifically, 56.1% of the sample (N = 65) reported good frequency of sexual activities before diagnosis, whereas with advanced cancer, only 3% reported ‘good’ frequency and 51.5% reported that they had no sexual intercourse. In regard to the ‘effectiveness’ of sexual activities, 66.7% reported ‘good’ effectiveness, whereas with advanced cancer, 77.2% reported ‘insufficient’ or no sexual activity. Finally, before diagnosis 83.8% reported ‘good’
satisfaction with sexual activities, whereas with advanced cancer, 75.8% reported ‘insufficient’ or no sexual satisfaction. This research indicates that not only do issues of sexuality and intimacy remain an important issue for palliative care cancer patients, but it appears that they experience greater problems relating to their sexuality during the palliative care stage of their illness compared to earlier cancer stages. However, these quantitative studies have not been able to unpack why palliative care patients experience greater sexual problems than earlier stage cancer patients. It has been speculated that it could be due to the greater degree of physical debilitation caused by advanced cancer, and because people with cancer have not been able to discuss sexual and intimate issues earlier in the cancer trajectory, as health professionals have not raised the issue (Redelman, 2008).

Further, it is also relevant to note that when palliative care health professionals position patients as already having adjusted to any sexual and intimate changes prior to reaching palliative care, they are able to position discussions of sexuality as not part of their role. Rather, having these discussions is positioned as the role of health professionals who are working with patients earlier in the cancer trajectory. Yet, as the above literature illustrates, given that palliative care patients experience greater disruptions to sexuality and intimacy than earlier stage cancer patients, it appears that there is a clear need, and role, for palliative health professionals to provide opportunity for palliative patients to discuss potential sexual concerns.

“Sex, Wouldn’t That Be The Last Thing They’d Think About When They’re Sick?”: Positioning Patients As ‘Too Ill For Sex’

Many health professionals reported that they did not raise issues of sexuality with some patients as they positioned palliative care recipients as not having the
physical capacity to be intimate due to the debilitating impact of their illness – being “too fatigued”, “nauseating” or in “too much pain” to engage in sexual and intimate practices. Kay, a counsellor, describes this positioning, and also adds that, by raising sexual issues with patients, it would remind them of another loss they would have to face:

Their body is quite different, and they physically don’t have stamina and energy. I think it’s one of the last things they would think of and I think most of the time they physically wouldn’t be able to have a full on sexual experience…so it would be like asking them to be a part of a two-k run or something, like it would be insulting, and on top of everything else that you have knocked out of your life, I’m going to bring up another that you can’t do.

Although admitting that this is a supposition, Helen, a nurse, also explains that due to low energy levels, palliative care recipients would no longer be interested in sexual issues:

This could be completely wrong, but I just get a sense that people, when they are at that stage of their life, that’s not what they’re thinking about…I just get a sense that that part of themselves has gone, because they’re not going to have that energy.

Likewise, Karen, a nurse, also says that due to high exhaustion levels, palliative care recipients would not consider sexuality an issue for them, and would be conserving their energy for treatments. Correspondingly, she also comments that, in her role, her focus was on the “clinical aspects of care”:

All their energies are perhaps going into other things. These sexual – sexuality or the contact is, at that point, not such a huge issue for them. It’s
actually just going through their treatments. So I think, as clinical nurses, we
tend to look at the more clinical aspects of people’s care…their exhaustion
levels are huge, that is the biggest issue, fatigue on a constant basis.

Some health professionals in my study noted that their positioning of patients as
being “too ill” for sex was an “assumption”, and subsequently often expressed regret
for not raising sexuality. For instance, Janine, a social worker, explains that she
commonly positions palliative care recipients as too ill to engage in sexual practices,
and consequently does not raise questions of sexuality with them. However, it is
noteworthy that she says that, by not raising issues of sexuality at all, she is also not
giving them the opportunity to discuss how they may feel about the changes to their
sexuality post-cancer:

I make an assumption that often a lot of the people are probably not sexually
active anymore because of how they describe their physical reality. But it’s
not something I check out…how bad their illness is impacting on their sexual
selves and their sexual experiences and how they feel about that and I think
it’s sad not to have that as an upfront part of the work we do and the work I
do.

Similarly, Andrea, a social worker, draws attention to the importance of challenging
the assumption that patients are too ill for sex:

An important tool is hearing the stories of people…it shatters the image of
“oh God, you know, sex and intimacy, wouldn’t that be the last thing that
people would want to think about when they’re sick?” and yeah, for some
people it possibly is, but it’s a pretty huge assumption to make!

The above two comments draw attention to the important point that if
palliative care recipients are positioned as being ‘too sick’ to be interested in
sexuality, then issues of sexuality are not raised with patients and they are not given the opportunity to explore concerns or losses around how their illness has affected their sexuality. Indeed, although some health professionals admitted that their positioning of some patients as being “too ill” for sex was a supposition, and subsequently expressed regret for not raising sexuality, it was apparent that despite this reflexivity, they still neglected to raise issues of sexuality. Further, whilst exploring changes to sexuality post-cancer is certainly an important issue for many patients, it is important to recognise that there are also some potential health risks that can arise if health professionals do not discuss issues of sexuality with palliative care recipients. Specifically, one health professional in this study (Dianne, a social worker) spoke of two separate cases where couples had become pregnant, and, due to the toxicity of the chemotherapy the patients were receiving, there was concern for the health of the foetuses. Dianne noted that on both occasions, the health professional teams involved (including herself), had not spoken to the couples about contraception and chemotherapy as they had thought the patients “just too sick” to be capable of engaging in sexual intercourse. Of the first couple, Dianne explained that:

One of our patients has just got his wife pregnant and he’s just so sick, that we were astonished [laughs], he’s just been so very sick that, you know, I just, I certainly didn’t think of him being sexually active, and of course they didn’t discuss it with anyone that they were planning for her to get pregnant…so we’re all like nervous relatives, waiting to see if this baby is going to be born well. Because the drugs could have very dire effects on the baby…probably more of our patients are more sexually active than we realise. But, as I said, you know, that’s when I thought, maybe, we need to be discussing contraception more frequently, along with all the other things.
Dianne also discussed a patient who “had just had to have a termination because she did get pregnant and the drugs were so terribly bad that they just decided it was just too big of a risk”. She noted that this experience for the patient was “horrible, that was a horrible grief because she was – and she said, you know, I was the sort of person that never thought I’d have an abortion”. Clearly then, both of these examples highlight the need for health professionals to not simply position patients as too unwell to engage in sexual activity, and point to the importance of health professionals also considering and raising issues of contraception and fertility with patients, particularly given that there are possible health risks involved.

It is likely that this positioning of patients as “too ill” for sex draws from a common social discourse that sexuality and illness are mutually exclusive, an extension of the notion that sexuality is for the young, able-bodied and disease-free (Gilbert et al., 2010a; Shildrick, 2005; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Accordingly, individuals who are sick and dying also become excluded from discourses of sexuality, and the idea that sick (and dying) individuals may have sexual needs or desire is considered taboo (Nyatanga, 2012; Redelman, 2008).

Equally, it was apparent that in most of the above accounts, health professionals were constructing sex as performance; a physical act requiring sufficient physical stamina, of which palliative care patients were positioned as lacking: “they’re not going to have that energy” (Helen), and, “they physical don’t have stamina and energy…it would be like asking them to be part of a two-k run” (Kay). This construction of sex as performance and sexual functioning draws from the dominant heterocentric biomedical discourse that privileges, and narrowly defines, ‘real’ sex as the coital imperative; that is, penis/vagina intercourse. It has been noted that, particularly in a palliative care context, health professionals are
likely to position discussions of sexuality as ‘irrelevant’ for palliative care patients, given they are viewed as ‘too ill’ for sex, and therefore positioned as unable to meet the required level of sexual functioning and stamina required for ‘real’ sex (Matzo & Hijjazi, 2009; Sundquist & Yee, 2003; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Whilst some patients may feel that they are too sick to engage in sex, and may consider that it is no longer an important part of their lives, it is problematic to assume that this will be the case for all patients, as some may still desire sexual intimacy, or may even, as was illustrated above, be planning a pregnancy. Further, as was evident in the above accounts, when health professionals position patients as “too sick” to engage in sexual acts, it often means that no discussion of sexuality and intimate issues will occur. Consequently, health professionals may not be able to offer alternative ways of expressing sexuality and intimacy that patients would feel able to engage in, for example, physical touch, and patients will not be given the opportunity to talk about their loss of sexual intimacy, or perhaps even feel it is permissible to experience desire or need for sexual intimacy (Gilbert et al., 2010a; Oskay et al., 2011; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). Equally, patients with advanced cancer have reported wanting to receive information about how they can safely manage their bodies during sex in order to minimise pain and still continue to experience pleasurable sex (McClelland et al., 2015). As such, it appears important that health professionals become able to challenge constructions of palliative care patients as being either focussed on “surviving” cancer and cancer treatments, and being “too ill” for sex - which, in particular, necessitates that health professionals would challenge constructions of sex as performance (McPhillips et al., 2001; Potts, 2002). By challenging these constructions, health professionals would move towards holistic care of the patient, where sexual and intimate needs are
recognised and accepted as a normal part of an individual’s quality of life, regardless of illness.

“If You’re Not In A Relationship, You’re Not Having Sex; If You Are In A Relationship, You’re Having Sex”: Positioning Un-partnered Palliative Care Patients As Having No Sexual Needs

Many health professionals appeared to position un-partnered people with cancer - who were often referred to as “single”, “widowed”, “never married”, or as a “spinster - as having no sexual and intimate needs. Instead, the accounts that health professionals gave about issues of sexuality and intimacy, and in particular, sexual expression, were often discussed in relation to people with cancer who were partnered. This positioning was aptly described by Andrea, a bereavement counsellor, who explained that, “it’s assumed, if you’re not in a relationship, you’re not having sex; if you are in a relationship, you’re having sex”. More specifically, the accounts health professionals gave reflected a common socio-cultural construction where un-partnered people are often not thought of as having sexual desire or needs (Fobair et al., 2006; McClelland, 2015; Ussher et al., 2012; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). For example, Jenny, a palliative care physician, whilst being reflexive about overlooking the sexual needs of un-partnered people with cancer, explained that she still found it difficult to recognise the needs of un-partnered patients:

I guess I feel most comfortable with people who are my age or younger, and especially with people who I know have a partner and have young children, I guess ’cause I think they’re most like me, and I know they’ve had sex fairly recently [laughs]…I carry my own prejudice even though I know they’re there and they’re wrong I still can’t get them out of the way!
Similarly, after I asked Kelly, a nurse, “are there times when you don’t raise issues of sexuality and intimacy?” she explained that with “single and widowed people, I don’t think of it then like I would if it was a couple”. And, Karen, a nurse, when asked the same question, recalled two recent interactions with “patients”, and explained that she did not discuss issues of sexuality and intimacy with either of them as they were un-partnered:

I’m just thinking of the people I’ve seen today, and I discussed neither [sexuality and intimacy] with either patient because they were both ladies living on their own. And maybe that’s my mistake…we talked about their quality of life today and they both said to me it was pretty horrible. But I didn’t drill it down into a part that – that intimacy was involved…We ask about their family. We ask about, you know, who’s doing the tablets. But we don’t ask them who gives them their last hug at night…but you know, we ask very basic things. For each of us it’s to go to the shower and wipe your bottom. And when that goes, we don’t explore it enough I don’t believe to say what does this mean for you? You know, what does this do to your dignity? And how does it change how you feel?... I think it’s drilling down more…

And maybe that is enough to open up doors and get people to respond.

In Karen’s account, it is apparent that she was reflexive about the sexual and intimate concerns that her patients may have had, and how she could have addressed them. However, importantly, it is interesting to note that sexual self-expression or desire was not mentioned in her account. Rather, issues of physical intimacy and sense of self were described, reflecting the socio-cultural construction that un-partnered individuals are not thought of as having sexual desire or sexual relationships (McClelland, 2015; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). This narrow
conceptualisation of sex as being only for those in relationships negates the fact that individuals do not need to be in a relationship to experience sexual desire or autoeroticism.

Further, in the accounts health professionals gave, it appeared that un-partnered people with cancer, who were considered “elderly”, were even less likely to have issues of sexuality raised and discussed with them. For example, after asking Julia, a doctor, whether there were times when she might decide not to raise the routine screening question about sexuality, she explained that, “oh, well, if you’ve got an 80-year-old spinster, I don’t usually bring it up. But I would normally have a bit of an idea about the family and their social situation”. In addition, when asked if there were cues that helped her to decide whether to ask about sexuality, Julia said, “well I think if somebody is elderly and never married. I don’t ask them”. Similarly, Margaret, a nurse, also remarks that “for the elderly, widowed parent, intimacy and sexuality mightn’t be much of an issue”.

Whilst many health professionals positioned all elderly and un-partnered patients as not having sexual and intimate needs, there is evidence to challenge this notion. For example, Gott and Hinchliff’s (2003) study illustrates that the sexual needs of un-partnered older people are diverse and varied. In their study, most un-partnered older people, typically widowed, reported that sexual activity was no longer a priority to them as they did “not want anybody else” after the death of their partner, or because they did not have a current partner. However, in contrast, two widowed participants reported that they missed sex, and another widowed participant said that since being widowed, she had started using a sex aid and reported that sexual pleasure was important to her. Similarly, another participant reported that sex had become more important to him since his divorce, despite not being in a current
relationship. Although this study was not conducted in the context of cancer and palliative care, it nevertheless highlights that un-partnered and older palliative care recipients are likely to have complex and varying sexual needs, of which they may want the opportunity to discuss with health professionals. Further, also important to note, is that although older and un-partnered palliative care recipients, particularly those who are widowed, may report that sexual activity is no longer important to them, many older people do construct sexuality as more than intercourse, and note that it also includes “companionship, looking and feeling one’s best, and enjoying explicit magazines and movies” (McAuliffe et al., 2007, p. 71). Consequently, it is important that health professionals provide opportunity to holistically address these other important areas of sexuality and sexual expression with un-partnered and older palliative care recipients.

Whilst most health professionals appeared to overlook the sexual and intimate needs of un-partnered palliative care recipients, a few health professionals I interviewed did give accounts which highlighted some of the sexual and intimate needs that un-partnered palliative care recipients can have, and which can be addressed. For example, social worker Pamela’s account of an experience she had with an un-partnered palliative care recipient illustrates how intimacy remained important for this individual, despite the significant physical symptoms he was experiencing:

I suppose the most approachable, the most useful approach for me is the one of physical touch. But the closest I’ve come, you know, back from just prior to this interview, is a man in his late 60s who’s a widower, and he’s just been in respite, he’s dying of pulmonary fibrosis, he’s already on oxygen, and he can have a conversation, but probably for not that long, and one of the things
he said to me when he was in respite, he said, he asked one of the nurses, ‘could he ask them a favour’, and she said ‘yes’, and he said, “can I have a hug?”, and she did give him a hug. And I thought well that, that really is a prime example I suppose of someone who may well be starved for touch, because of his personal circumstance [being un-partnered] and, and you don’t realise that a man who’s struggling for breath, might also have other priorities as well like physical touch, and he’d ask another nurse on another occasion if she would just sit there and hold his hand, and I guess it’s those kind of things that – that mean a lot to somebody who, who maybe doesn’t have anybody else to touch them. Or who has not felt a female touch in any way much, for a very long time”.

Another social worker, Heidi, described how a female un-partnered palliative care recipient who had recently entered a new relationship did not want to proceed with a necessary surgery due to concerns that she would not be able to have sexual intercourse following this treatment. Heidi explained that when the woman received the opportunity to discuss her sexual concerns and alternative ways of expressing intimacy with her new partner, she chose to proceed with the surgery:

I remember really, really early on, very early on in that - probably only been here about six months and the consultant - one of the consultants rang me and said, “Oh Heidi I want you to ring this woman. I've seen her, she's an older woman who has endometrial cancer and I've scheduled her for surgery next week and she's rung to say that she wants to cancel it.” And he said, “She needs the surgery [laughs], she's got endometrial cancer. Would you mind ringing her?” So I did ring her and this is over the phone. And what happened was it - she'd been widowed for several years. She'd met a lovely
new man, and was just embarking a new relationship with him. Had not had any sexual contact but certainly had intimate contact but no intercourse. And she was devastated to think that she might not be able to have intercourse with him after the surgery. And so she wanted to - she said I don't want to cancel the surgery altogether. I want to put it off long enough that I can really feel like this relationship is going to last and then do it. So I got her to come in and we revisited the sort of change - I got the surgeon to revisit the changes of what would happen as a result of the surgery. So yes you would have a surgery that removed your uterus and tubes and ovaries and your vagina would be a little shorter. However, sexual intercourse would still be possible. There are other ways of expressing yourself intimately and so on. And - and she then went ahead with the surgery. And didn't at that point want me to talk to her partner because it still a very new relationship but they were able to sort that - once she was clear that her - that with some modification to what she's been used to before with her deceased husband, she would be able to resume a normal sexual relationship; she was happy to proceed.

The above two accounts illustrate some of the sexual and intimate needs that un-partnered palliative care participants can have. In particular, Heidi’s account illustrates how palliative patients may make decisions to delay or stop treatment because of concerns about how sexual changes caused by cancer treatments may impact their newly formed relationships or their capacity to enter new relationships in the future. These two accounts also highlight how health professionals can respond to the needs of palliative care patients, by providing information about how their sexuality will be affected by cancer and cancer treatments, and by offering alternative ways of expressing sexuality and intimacy.
If we look at the sexuality and palliative care literature, there also appears to be an absence of studies examining the sexual needs of un-partnered palliative care recipients. For example, in one of the most cited studies in the area of sexuality and palliative care, which examined the meaning palliative care recipients gave to sexuality, the inclusion criteria required that participants be “in a current relationship with a partner” (Lemieux et al., 2004, p. 631) negating the views of un-partnered individuals. Similarly, Vitrano, Catania, and Mercadante’s (2011) quantitative study, which examined sexuality of patients with advanced cancer, also did not include un-partnered people with cancer in their study. Additionally, key opinion pieces and review articles (e.g. Blagbrough, 2010; Redelman, 2008; Stausmire, 2004) in the area of palliative care, cancer and sexuality have also not made mention of the sexual and intimate needs of un-partnered individuals, with only one review article (Cort et al., 2004) exclusively exploring the sexual and intimate needs of “couples in palliative care” (article title). The lack of un-partnered people being included in palliative care and sexuality research may reflect a conflation that the sexual needs of partnered people with cancer are the same as those who are not in a relationship.

However, if we look more broadly at the cancer and sexuality literature, more recent studies have looked at the sexual needs of un-partnered patients (see Hordern & Street, 2007a, 2007b; McClelland, 2015; Parton, 2013; Ussher, Perz, et al., 2011; Ussher, Perz, & Gilbert, 2015), and found that as a group they may experience more sexual problems in some areas compared to those who are partnered. These sexual problems include: experiencing greater levels of sexual dysfunction despite reporting sexual desire (Tuinman et al., 2010), and reporting greater feelings of sexual unattractiveness (Fobair et al., 2006). Research has also found that un-partnered people with cancer often raised concerns about entering new relationships (Ussher,
Perz, & Gilbert, 2015). For example, in one study of women with breast cancer, 57% of women (N = 236) reported that the sexual changes they had experienced had impacted their ability to enter a new relationship (Ussher et al., 2012), with body image and attractiveness (77.2%, N = 196) the most frequently identified issue. Further, of those who were considering entering a heterosexual relationship, 65% (N = 165) reported ‘not feeling desirable’, and 46.5% (N = 118) reported ‘fear of rejection’. Single women also identified ‘fear of sex will be different’ (20.9%, N = 53) and ‘fear of physical pain’ (14.2%, N=36) as other concerns relating to their ability to enter new relationships. Finally, it has also been found that regardless of partnership status, people with cancer still want the opportunity to discuss and receive information about issues of sexuality with health professionals (Hordern & Street, 2007a, 2007b). However, un-partnered patients have also reported feeling as though they are largely invisible to health professionals, who reportedly have rarely communicated about post-cancer sexual issues with them (Ussher, Perz, & Gilbert, 2013). These studies support the notion that un-partnered people with cancer have sexual and intimate needs which can be addressed by health professionals, though clearly, given the paucity of studies in the area of palliative care, further research is needed to give voice to the sexual needs and information requirements of un-partnered people with cancer in a palliative context.

“It’s Quite Different to Straight Culture”: Difficulties in Responding to the Needs of Non-heterosexual Palliative Care Patients within a Heteronormative Discourse

A few accounts given by health professionals illustrated how the dominant discourse of heteronormativity caused difficulty for health professionals to respond to the sexual needs of palliative care recipients who were not in ‘traditional’
heterosexual relationships. The hetero-centric view of sex emerges from narrow biomedical constructions of sexuality that privilege ‘real’ sex as penis/vagina intercourse, rather than viewing other forms of sexual expression as equally valid. For instance, Helen, a nurse, explained that she would find it difficult to address sexual issues with palliative care recipients who were “transsexual” or “gay”, as it was a “different culture” to the “straight culture”:

I suppose you get your transsexual people, ah gay people…so I know that I’m not particularly comfortable with that. So if you were looking after someone who was, and I have looked after um, ah, gay people before, but I think it’s quite a different culture, and I think um, to the straight culture, and I think that would be hard. It’s hard for both parties.

What is noticeable in Helen’s account is her use of othering language, “you get your transsexual people, ah gay people”. Here, we can see a conflation of transsexual with gay; which works to create a dichotomised division between “straight” and ‘non-straight’ “culture”, rather than appreciating the myriad of ways that sexual identity can be experienced and expressed. This use of othering language serves to construct non-heterosexual individuals as a marginalised, alien group, who possess “quite a different culture”, from the heterosexual group. Accordingly, it is perhaps, by magnifying projected differences between ‘straight’ and ‘non-straight’ culture, which leads to discussions of sexuality with non-heterosexual patients as being construed as “hard” by Helen. Indeed, it is instructive to note Helen’s hesitation “ah” before saying “gay people”, on both occasions of utterance. This hesitation, “ah, gay people” appears to denote her discomfort with speaking about “gay people”. Further, and equally important, not only does othering language function to amplify projected apparent differences between groups, but it also functions to reinforce and reproduce
the position of dominant and subordinate groups. Consequently, it has been noted that groups and “…persons who are treated as other often experience marginalisation, decreased opportunities, and exclusion” (Johnson et al., 2004, p. 254). And, indeed, in studies of health professional practice in the context of cancer care (see Fobair et al., 2002; Hyde, 2007; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013), it is evident that, reflecting the dominant heterocentric biomedical discourse of sex, the sexual needs of those who identify as non-heterosexual have been marginalised and overlooked.

In addition, not only did some health professionals in my study experience personal discomfort in talking about sexuality with non-heterosexual people with cancer, but some health professionals also discussed how on an institutional level, standard hospital forms promoted inequality and caused difficulty for those who wanted to practice inclusively. For example, Carla, a social worker, explains that although she is comfortable addressing sexual issues with “same sex” palliative care recipients, she finds that the standard hospital forms are a barrier as they do not use neutral language when referring to the patients’ relationship status:

…and one of the things I raised was in our mission sheet, it’s geared up towards marriage, you know, wife, husband. It’s not partner, you know, same sex, whatever. And they’re asked, you know, ‘do you have a wife or a husband? They’re not asked, ‘do you have a partner?’ So whether on that initial admission if there was more inclusiveness around that, perhaps people would – would know that it was okay to be more open. It seems to be a very silent thing.

Other authors (Cagle & Bolte, 2009; Cort et al., 2004) have also noted the importance of health settings using inclusive terms such as ‘partners’, rather than
‘husband’ and ‘wife’ - the latter being language which legitimises a conservative form of relationship expression, which even heterosexual de-facto couples would be excluded from. Accordingly, Carla’s account highlights how conditions for othering practices can also be promoted on an institutional level (Johnson et al., 2004). Thus, what we see in both Helen’s and Carla’s accounts is how the use of othering language, often used without critical awareness by health professionals, can undermine laudable goals promoted within health care settings, which value equality and diversity of patients. Rather, when othering language is used, it works to prevent health professionals from seeking to understand and respond to the sexual needs of all people with cancer, irrespective of their sexual and gendered identity. It is, therefore, important to identify the use of othering language within health care settings, and transform it through more intentional use of inclusive language, so that equity within health care settings can be better supported.

“For Men who are Going Out and Having a Good Time”: Positioning Men as Having Greater Sexual Needs than Women

In some of the accounts, health professionals appeared to draw on the dominant heterocentric socio-construction of sexuality – produced by biological theories of sexuality – which positions men as “biologically driven to have sex (whereas women are not)” (Ussher, 1997, p. 313). As Andrea’s (a bereavement counsellor) account illustrates, when drawing on this discourse, health professionals can often position male partners as missing sex more than female partners:

I think someone to make assumptions that the man might be the person who – if it’s a heterosexual relationship – you know, if the man is unwell, you know, he’s missing out on having sex with his wife. But it might be her who is the one who is very distressed because she was the more dominant, the more
expressive of the intimacy and sexuality that might’ve been a bigger part of that intimate relationship.

The positioning of men ‘needing’ sex more than women is also evident in Maureen’s account, who explains that if she were working with “young single men who were going out and having a good time”, and particularly if they had a “prostate cancer or something like”, then issues of sexual expression would likely be discussed more:

Well it [sexual expression] rarely comes up, as I said a lot of people are elderly, it’s not something they probably talk about much, people in their 80s and 90s. We’ve got a lot of, quite a lot of widows, a lot of single people. So a lot of them [conversations] are [about] emotional intimacy, rather than sexual intimacy…but yeah, it hasn’t come up, like, if I was dealing with predominantly 25-year-olds, or maybe young single men who were going out and having a good time, and have a prostate cancer or something like, that might be much more topical.

Accordingly, in Maureen’s account, we can see reflected this dominant socio-cultural discourse of sexuality – which has been termed the male sexual drive discourse (Hollway, 1984a)- where men are constructed as actively seeking, and innately requiring, sex, (“going out and having a good time”), whereas conversely, women who exhibit greater desire than men tend to be positioned as having a problem (Ussher, 1997). Furthermore, when Maureen discusses the sexual needs of “young single men” in relation to “prostate cancer and the like”, Maureen’s account again reflects this hegemonic discourse of sexuality, which also frames ‘sex’ as equivalent to heterosexual intercourse (Gavey, McPhillips, & Braun, 1999; Tiefer, 1996):

In a similar vein, Jenny, a palliative care physician, when giving an account of how comfortable she felt about discussing masturbation, begun by talking about it
in relation to male patients, before correcting herself to state that she had not included female patients:

Yes, so from this course [a sexuality workshop for health professionals] I did, I did think ‘oh would I be happy about talking to a bloke about masturbation?’, and I think I would be. Um, it hasn’t happened, and...I don’t know whether that’s because I’ve never asked or because of, a bloke would never ask, would never feel comfortable with that, I’m not sure...And now, I will bring it up if I feel...that there’s something that they want to talk about...

Um, you know and, and...yeah I should add to that I’ve never had a female ask me about masturbation either, I’m just assuming that it’s blokes.

(italics added for emphasis)

The above accounts, which suggest that palliative health professionals were more likely to recognise and raise sexual issues with male patients, echo the findings of another study which examined cancer patients’ and their partners’ experiences of sexual communication with health professionals. In this study, it was found that male cancer patients and their female partners were more likely to have had sexuality discussed with them by health professionals than female cancer patients and their male partners (Gilbert, Perz, & Ussher, 2014). As such, the findings of this study and my study both add support to the notion that the adoption of the male sexual drive discourse is likely to impede palliative care health professionals’ recognition of the sexual needs of female cancer patients. Yet, if we look at the cancer and sexuality literature, numerous studies (e.g., Parton, 2013; Ussher, Perz, et al., 2011) have demonstrated that people with cancer experience significant sexual changes regardless of gender. This includes, for example, both men and women with cancer reporting sexual dissatisfaction, limited or no frequency of sex, and insufficient or no
sexual satisfaction (Vitrano et al., 2011). Finally, it should also be recognised that when health professionals draw on heterocentric constructions of sexuality which frame ‘real’ sex as heterosexual intercourse, as Maureen did in her account, they can overlook the needs of people with non-reproductive cancers; a great oversight given that significant sexual changes are also experienced by many people with non-reproductive cancers (Perz et al., 2014; Shell, Carolan, Zhang, & Meneses, 2008; Traa et al., 2011) and their partners (Hawkins et al., 2009). As such, the findings of this study suggest that health professionals would benefit from training which would undermine the cultural constructions of sexuality which position men as having more sexual needs than women, and which construct ‘real’ sex as heterosexual intercourse and functioning.

**Conclusion**

In this analysis I have demonstrated how participants, by drawing on wider discourses of sexuality, illness, dying, and aging, positioned some people with cancer as “not needing to know” about cancer. The adoption of these discourses appeared to limit many health professionals from even recognising the sexual and intimate needs of patients. However, I also argued that these discourses could be drawn on by health professionals as a discursive strategy to excuse themselves from addressing the sexual needs of patients.

When health professionals drew on the cultural discourse that sexuality is for the young and able-bodied (Hinchliff & Gott, 2008; Hordern & Currow, 2003), older patients were positioned as outside the boundaries of sex; having no sexual desire or interest in sex. Further, by drawing on this discourse of asexual aging, older patients were also positioned as experiencing discussions of sexuality as taboo, leading health professionals to report avoiding discussions of sexuality in case they caused offence.
However, drawing on this discourse also allowed health professionals opportunity to legitimise their avoidance of raising sexuality by constructing themselves as sensitive and considerate for not doing so. Yet, it is possible that health professionals were also avoiding these discussions because of feelings of embarrassment, or feeling that they lacked knowledge and skills to respond to such a ‘private’ issue (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

Most participants also drew on the biomedical discourse of sexuality, which privileges ‘real’ sex as heterosexual intercourse, previously described as the coital imperative (McPhillips et al., 2001). Accordingly, through constructing sex as performance and sexual functioning, many palliative care patients were deemed ‘too ill’ for sex; in other words lacking the physical stamina required for penetrative sex. This construction of sex also led health professionals to overlook the needs of several patient groups. Firstly, some health professionals found it difficult, on a personal and institutional level, to respond to the needs of patients who were un-partnered or who identified as non-heterosexual. In particular, I illustrated how the use of ‘othering’ language can lead palliative health professionals to construct a dichotomy between “straight” and “non-straight” culture, which works to reinforce the marginalisation of non-heterosexual patients. I also discussed how othering practices can be incited on an institutional level, when health settings neglect to use inclusive terms such as ‘partner’, rather than ‘husband’ and ‘wife’ on their forms; therefore legitimising one form of relationship expression (marriage) whilst excluding others. Secondly, I also illustrated how some health professionals overlooked the sexual needs of women, by drawing on the biological discourse of sexuality which positions men as needing sex more than women (Hollway, 1984a; Ussher, 1997).
As I demonstrated in this analysis, when these taken-for-granted constructions of sexuality, illness, dying, and aging are uncritically accepted by health professionals, it can create difficulty for them to recognise the sexual needs of patients who fall outside the boundaries of these constructions of sexuality. Further, there is also a capacity for health professionals to legitimise their avoidance of discussing sexuality by positioning some patient groups as easily offended by discussions of sexuality, or as not having any sexual needs. The result is that many people with cancer, who may still have sexual desire or concerns which they wish to discuss, are not afforded this opportunity. This lack of sexual communication is a significant issue considering that most palliative care patients and their partners wish sexual issues to be raised by the health professional, due to feelings of embarrassment or feeling that it is inappropriate to do so themselves (Hordern & Street, 2007a). As such, these findings suggest that it would be helpful for palliative health professionals to receive training that will both encourage them to challenge these sexual myths, and also become reflexive about how the language that they may use to describe patients may (re)produce these sexual myths. Such training would also contribute to health professionals recognising sexuality as a central part of quality of life for many palliative patients - regardless of age, gender, sexual identity and illness (McClelland et al., 2015; Ussher, Perz, & Gilbert, 2015).
Chapter Six: Influence of the Biomedical Discourse on Health Professional Practice and Palliative Care Settings

In this chapter I will examine how the biomedical discourse infiltrates and shapes the care practices of health professionals in potentially problematic ways. The first key issue that will be addressed is that ‘non-medical’ sexual and intimate concerns, specifically, psychosocial sexual changes, are not positioned as a legitimate part of the ‘medical role’ (Pringle, 1998; Tiefer, 1996). Consequently, it was reported that medically-trained health professionals often experienced difficulty in holistically responding to patients’ sexual and intimate needs because these needs diverge from what is positioned as ‘important’ within the biomedical discourse. Further, allied health professionals, such as psychologists and social workers, also reported difficulty in responding to the sexual and intimate needs of patients because they were constrained by working within a medical system which prioritised ‘medical’ issues.

The second key issue that will be addressed in this chapter is the differences which were identified in health professionals’ accounts between the hospital, hospice, and community care spaces, and the consequences of these differences on the sexuality and intimacy of palliative care recipients. The hospital space was discursively constructed as an extension of the “medical system”: a space effective at responding to physical aspects of wellbeing, but unconducive to responding to psycho-social aspects of wellbeing, such as sexuality and intimacy. The hospice space was constructed as the intersection of the hospital and community – often embracing and having capacity for more holistic care. However, the hospice space was still impacted by the dominance of the biomedical discourse in health care settings. Lastly, the community care space - the home of palliative care recipients -
was constructed by health professionals as a “safe, sacred space”, and much more conducive for recipients to maintain and express their sexuality and intimacy.

I will begin by arguing that because sexuality is not positioned as part of the medical role, health professionals experienced difficulty addressing sexuality and intimacy holistically.

“All the Touchy-feely Stuff Are Not Seen as a High Priority”: Sexuality and Intimacy is Not Positioned as Part of the Medical Role

As I outlined in Chapter Four, even though medically-trained health professionals positioned discussions of sexuality and intimacy as an important part of the holistic care they provided to patients, they reported that the “medical culture” which was present in a hospital setting did not support their attempts to practice holistically. The following account from Jennifer, a palliative care physician, illustrates the difficulty experienced in being able to respond to the sexual needs of patients, as a result of medical issues being often viewed as more important by the medical staff:

I think the only other thing I was just thinking about then is that certainly in the hospital environment all the touchy-feely stuff, like emotions, are not seen as a high priority. So even if I said to a home team or a group of professionals in the hospital, “Oh, look, the most outstanding thing for this woman is to get home and be with her husband tonight, ‘cause it’s their anniversary and they want to have hot sex”, you know, they’d be horrified by that, they’d be like, “well she needs her antibiotics at six-thirty”, and you know, ‘she can’t possibly go home’, you know it’s just not seen as a high priority in terms of quality of life, or well, quality of life is not seen as a high priority in a hospital I guess that’s the bottom line. The physical things are more important
like whether you’ve got a line in or whether you’re allowed to eat or not, and I guess I’m fighting against that all the time, I’m saying well, “he’s dying, and I think well we should forget about his diabetes and he can eat whatever chocolate he likes”.

In the above extract, Jennifer, as a palliative care specialist, positions herself as a holistic practitioner responding to the ‘total pain’ of the patient - encompassing emotional, physical and spiritual forms of suffering - as required by the palliative care discourse (Mino & Lert, 2005; Pastrana et al., 2008). However, as her account highlights, the hegemony of the biomedical discourse present within this hospital setting constrains her efforts to respond holistically, and thus she constructs herself as an active subject resisting this discourse, “I’m fighting against that all the time”, through advocating the holistic care of patients. Additionally, Jennifer’s assertion that “quality of life is not seen as a high priority in a hospital” appears to me to be an ironic statement, however again illustrates the point that within a biomedical discourse, ‘patients’ are positioned as “diseases to be fixed” (Kearsley & Cassell, 2014, p. 53). Yet, as has been recognised elsewhere, such an approach, which centres on only treating physical disease, disallows medical health professionals from recognising how having the disease subjectively affects ‘persons’ (Kearsley, 2014).

Also of interest here is Jennifer’s use of the phrase “touchy-feely stuff, like emotions”. “Touchy-feely stuff” is a term that trivialises and minimises the emotional experiences of patients, and Jennifer’s use of this term here serves to highlight how the emotional needs of patients are deemed secondary and less important than the physical needs of patients within a medical context.

Jennifer was not alone in her account. A number of other health professional accounts highlighted that because issues such as sexuality and intimacy are not seen
as a legitimate part of the ‘medical’ role, physicians and nurses often feel more comfortable discussing the “technical, medical” aspects of sexuality. Namely, sexual functioning, rather than the patients’ emotional experience of changes to their sexuality. As Ken, a palliative care physician, reports:

Now, as far as the sexuality side of things go, I guess the one thing that most often arises and - and again I feel deficient being able to talk about this. But for example, somebody getting a new ostomy and how that affects their self-image and their, um, uh, ability to relate, uh, in a sexual sort of way because they have this bag hanging off them. Those are the things where I feel like I need to - I need to be able - I probably needed more training than I have in that. But as far as, you know, intimacy goes, I encourage people to climb up in the bed if they want. And be able to kiss on somebody and hug up on them. I don't find it difficult at all to talk about expressing intimacy and appreciating those relationships. And I've had conversations with people about erectile dysfunction, for example. So, um, you know that's - that's kind of technical medical advice essentially. It's not really talking about sexuality and how important it is to them and how you know things have affected their relationships. It's talking about you know can they get an erection or not [laughs]?

In Ken’s account we can see a separation of sexuality and intimacy, including how patients experience re-negotiating their sexual relationship after post-cancer sexual changes, which is contrasted with acts of intimacy, such as hugging and kissing. Within this account, intimacy is deemed easier to talk about than sexuality. For example, Ken not only reports difficulty in speaking about sexuality, but the pauses in his account, and his euphemistic way of describing patients ‘having sex’, also
appear to illustrate his discomfort in doing so, “and their, um, uh, ability to relate, uh, in a sexual sort of way”. This likely reflects a larger social construction of sexuality as a taboo issue that should not be discussed, whilst on the contrary, intimacy can be publically displayed and talked about (Nyatanga, 2012; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

But beyond the separation of sexuality and intimacy, Ken also constructs a dichotomy between sexual functioning, “can they get an erection or not”, and ‘non-medical’ psycho-social aspects of sexuality, such as how “self-image” is affected after “getting a new ostomy”. Whilst Ken reports often raising “technical, medical” issues of sexual functioning with patients, he reflects that he feels “deficient” talking to patients about their emotional experiences of sexual changes. Accordingly, he reports that he needs “more training” to address those issues. Similarly, Linda, a psychologist, reports that the oncologists she worked with experienced difficulty in responding to sexual issues that diverged from sexual functioning:

If it [sexual changes post-cancer] was talked about, it was talked about in a really sort of perfunctory sort of way. “You’ll need to use this dilator” or, “you’ll need to do that”. And I know that the oncologists were very uncomfortable about talking about those things. See, it puts a huge pressure on the patient to have to mention it themselves. And some of the doctors were really good, but they would always, you know, there would often be this sort of anxiety about talking about things. And almost cutting somebody off and immediately talking about Viagra or a PDE5 inhibitor or something like that. I think often a sort of jump to medical conclusions or pharmaceutical conclusions rather than any sort of self-help strategies or psychological sort of stuff.
Like Ken, Linda reports that the oncologists she worked with also experienced “anxiety” in offering treatment or support regarding the patients’ “psychological” experiences of sexual changes. Accordingly, both these accounts illustrate an incongruence between what health professionals with medical training are comfortable discussing; the ‘medical’ physical aspects of sexuality, and what patients have reported wanting to discuss; their emotional, relational and physical experiences of sexual changes - an incongruence that has been highlighted in other studies (Byers, 2011; Herbenick, Reece, Hollub, Satinsky, & Dodge, 2008; McClelland, 2015; White et al., 2013). For example, one study, which included a sample of people with cancer and health professionals, found that there were “mismatched expectations” (p.225) between these two groups (Hordern & Street, 2007a, 2007b). Specifically, health professionals were mainly focussed on medicalised aspects of sexuality, such as whether patients were able to have sexual intercourse, and how the cancer treatments impacted their erectile function, fertility status and menopause. Whereas, the patients wanted their subjective experience of sexual changes heard by health professionals, and to be given practical support around how they could adjust to the sexual and intimate changes experienced post-cancer treatment, even when sexual performance had not been affected. This finding has also been observed in a study involving a sample of nurses, who reported that although they felt comfortable in addressing the physiological side effects that patients may have to cancer treatments, such as nausea and vomiting, they felt less comfortable in discussing how these changes to the patient’s body could affect the patient’s subjective view of their sexual identity (Lavin & Hyde, 2006). Therefore, it appears that medically trained health professionals find it difficult to respond to the emotional and relational aspects of sexuality, because these issues diverge from what
is positioned as important with the biomedical discourse in which they are trained.

Moreover, these accounts illustrate how the body of a person with cancer becomes constructed as a clinical object following a medical diagnosis. Under this medical gaze, bodies are reduced to the level of physical functioning, with illness, contained within the physical body, the focus of the medical gaze (Foucault, 1975). Within the positioning of the body as clinical object, the patient’s sexual subjectivity is not considered by health professionals. The illness is the focus of care. Accordingly, this positioning removes patients’ bodies from discourses of sexuality, femininity, and masculinity, with patients’ bodies positioned as ‘asexual’.

However, whilst the positioning of the body as an ‘asexual’ clinical object serves to limit health professionals’ consideration of patients’ sexual subjectivity, it can also function to protect patients and health professionals. Positioning the body in this way enables medical professionals to perform examinations and treatments on the ‘private’ and sexual parts of patients’ bodies, the breasts and genitals, without feelings of embarrassment, and also may function to minimise patients’ potential feelings of vulnerability about being ‘exposed’. For example, in a study of women with cancer, it was found that due to the asexual positioning of their bodies within a medical setting, many participants did not feel embarrassed exposing their breasts and genitals to medical health professionals (Parton, 2014). Whereas, the women in this study noted that outside of a medical setting, they would feel embarrassed exposing their ‘private’ bodies in a public space to non-intimate others. Thus, the positioning of patients’ bodies as clinical object can serve to protect patients and health professionals during medical procedures which expose the sexual and ‘private’ body. Yet, as I have illustrated, the positioning of the body as a clinical object can also be problematic, as it creates difficulty for medically trained health
professionals to address, or even consider, the psychosocial sexual needs of patients.

Another issue to consider is the training received by medical professionals. Whilst medical health professionals receive training to address sexual functioning, they are not taught skills to also address the emotional and relational aspects of sexuality. Like Ken, medical health professionals in other studies, specifically doctors and nurses, have also reported a lack of adequate training to address sexual and intimate issues, and have asserted that they would feel better equipped to address such issues if they were to receive such training (Hautamäki et al., 2007; Lindau et al., 2011; Oskay, Can, & Basgol, 2014; Stead et al., 2003; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Further, it is also worth pointing out here that the critique that medical health professionals have not received training to recognise and respond to the emotional and relational components of patient suffering is not confined to sexuality. More broadly, there has been a critique of the current limitations of medical training, in which, despite a shift to a more humanistic approach over the last few decades (MacLeod, 2000), health professionals are predominantly taught to focus on functioning of the body. Specifically, it has been widely argued that medical health professionals are trained as ‘applied scientists’, with medical training overemphasising objective logico-scientific thinking in treatment of physical dysfunction, whilst concurrently devaluing the subjectivity of patients, and encouraging detachment in health professional-patient relationships (Frankel, 1995; Kearsley, 2014; Shapiro, 2011). Therefore, such training appears to limit the discursive positions that medical health professionals are likely to adopt in regards to responding to sexuality, as the findings from my study and others (Hordern & Street, 2007a; Lavin & Hyde, 2006) indicate.

Given the recognition that medical health professionals have not received
adequate training in addressing the emotional, relational and physical components of sexuality (Hordern et al., 2009), some programmes have been developed with the aim of redressing this issue. Evidence has suggested that these programmes have been effective in increasing confidence and frequency of discussing sexuality, and in challenging normative assumptions about the sexual needs of patients, such as the myth that sexuality is not important to many older people (Hordern et al., 2009; Rosen, Kountz, Post-Zwicker, Leiblum, & Wiegel, 2006). Therefore, it appears that such training not only allows medically-trained health professionals to feel better equipped to address sexuality with their patients, but that it also may assist in re-positioning the emotional and relational components of sexuality as an important, and legitimate, part of their role.

‘There’s no space for it’: lack of time in the clinical context.

Another issue which health professionals from both hospital and community care settings reported as a barrier to discussing sexuality, was the lack of time they had allocated to consult with patients. For example, Brian, a nurse, says, “holistic care is a big part of what we try to do, it’s like an ideal. The reality is we don’t have the time”. Kelly, a nurse, also reports that there is no time to raise sexuality:

There’s so many times that I feel like it would be an issue but by the time I talk about their nausea and their constipation and their pain and get equipment into their house, you know, an hour or two hours goes by and there’s – there’s no space for it.

Jean, speaking about the hospital context, also explains:

It’s definitely in the inpatient setting because acute hospitals tend to be I guess, dealing with acute care, such as observations, giving of medications, showering…it’s so driven financially, and it’s [sexuality] never included, in
the nurses’ time of how much time you should actually sit down and assess a patient’s needs, and outpatients, there is time for doing observations, there’s time to do rounds, but if that is not incorporated into the time, it doesn’t happen.

Additionally, a number of health professionals added that they also lacked enough time spent with patients to develop the rapport necessary to broach a discussion about sexuality. As Madeline, a psychologist, explained:

To have these conversations with people demands a certain level of rapport with the patient. And yeah, a 10-15 minute rush to consult talking about other symptoms and problems – medical problems, I just don’t think it leaves a lot of space for it.

Dianne, a social worker, says:

I suppose, what I’d really like to do differently, but I just don’t know that I can, but I would like to see people more often. I think that if I had the opportunity to meet with them regularly over the time with us, then you would be able to go deeper into some of those issues that they bring up. But I just cannot do it with the time restraints that I have.

These accounts confirm previous reports of health professionals citing time constraints as a barrier to raising sexuality in the cancer context (Hautamäki et al., 2007; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013; Wiggins et al., 2007). It can be argued that these time constraints exist due to the current structure of medicine, as it is primarily informed by the biomedical discourse. There are two ways in which the current structure of medicine may function to produce the barrier of time constraints within clinical settings, which reportedly delimited participants’ capacity to discuss sexuality. The first is through the subject positions that medical health
professionals can adopt within the biomedical discourse. Specifically, doctors and nurses, with knowledge of medical science and the power to heal, are positioned by themselves, and patients, at the top of the professional hierarchy (Foucault, 1963). As such, they have opportunity to adopt the position of the ‘busy’ and ‘important’ health professional who are ‘healing’ the physical suffering of patients, with no time to discuss ‘trivial’ issues such as “the touchy-feely stuff, like emotions”, including, sexuality and intimacy. Secondly, however, there are also material components to time constraints in health care settings. These include overbooking of patients, and - as Jean mentioned in her account - limited time allocated to consultations, wherein the focus of consultations is directed at responding to “medical problems”, as per the biomedical discourse (Hordern & Street, 2007a). As Jean highlighted, when making the point that nurses’ rounds are structured around particular tasks that must be accomplished within established time frames, many health professionals are often unable to change these time constraints present in health care settings. Thus, it is apparent that the time constraints within health care settings offer limited discursive positions that medical professionals can take up in relation to addressing sexuality, with health professionals expected to practice in accordance with privileging care of the physical.

However, health professionals’ lack of agency in being able to remove time constraints in clinical settings may also make available another subject position which health professionals can draw on to justify any avoidance of sexuality. By drawing attention to the limitations of clinical schedules within health care settings, health professionals may also be able to adopt a position of helplessness, and absolve themselves of responsibility for raising sexuality. For example, by explaining that they do not have the time to build the “certain level of rapport” that is ‘required’ to
broach sexuality, health professionals may be using a discursive strategy to justify their avoidance of raising a subject they feel uncomfortable discussing, as I outlined in the previous chapter. In other words, by not raising sexuality “when conditions are not ideal for doing so” (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013, p. 1384), health professionals are able to position themselves as ‘sensitive’ and ‘considerate’ health professionals, operating in the best interests of the patients. However, as health professionals in this study, and in another (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013), have highlighted, there are times when health professionals are able to overcome these time constraints. For example, through the provision of written information about the sexual changes that patients and partners may experience post-cancer.

In sum, these accounts illustrate that time constraints across all health care settings can limit health professionals from being able to adopt a subject position which allows them to better support the delivery of holistic care, including raising sexuality, to all patients. However, it is also important to identify and challenge the discursive strategies that health professionals may use to justify their avoidance of raising sexuality. Instead, whilst acknowledging the material limitations of health care settings, it is important to consider ways that health professionals may be encouraged to adopt a position of agency and responsibility in respect to addressing sexuality, and thus, seek ways in which time constraints can be at times mitigated (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

**Barriers to addressing sexuality within a multidisciplinary team.**

On a broader level, some health professionals also commented on the physical and psycho-social dichotomy that they reported exists in health professional roles. In particular, that medical staff position “basic biological function” as part of
their role and skills set, and emotional issues such as sexuality and intimacy are positioned as part of the role and skills set of social workers and psychologists. As Madeline, a psychologist working in a hospital, reports:

I think it’s pretty much about that bio-psycho-social model of health, and the doctors and medical clinicians perceive that they deal with that [biological] bit, and then because there are identified clinicians in the hospital such as social workers and psychologists, they deal with the other bit [psycho-social].

Whilst adherence to a model of multi-disciplinary practice is necessary to achieve whole person care, there is evidence to suggest that this does not always occur in practice. For example, Madeline goes on to explain that if medical health professionals do not identify sexual issues that may be better addressed by allied health professionals, then referrals to allied health professionals may not be facilitated:

I think the ideal is that, not just for patients’ issues around sexuality and intimacy, but around all of their needs and issues as a whole person, is that they get a full medical service as well as a full psycho-social support service. And for that psycho-social assessment to cover sexuality and intimacy. But the reality is that very few patients get access to that. And most patients – if they do have issues around – have questions or issues around sexuality or intimacy, unfortunately the responsibility probably falls on them to raise those issues with their medical or nursing clinicians in order to then get the answers and/or referral on to someone that can help with that.

Madeline’s account illustrates the importance of health professionals having clear communication and referral pathways to facilitate effective multidisciplinary management of sexual issues. Given that medical staff have more frequent and
ongoing contact with patients than allied health professionals, it would appear
helpful for medical staff to receive training that would enable them to feel confident
and equipped to discuss any sexual concerns that patients or partners may have
(Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). This is particularly important
given that currently, many doctors and nurses report that they do not routinely raise
sexual and intimate concerns with patients (Flynn et al., 2012), and most patients do
not raise sexual concerns due to feelings of embarrassment, or feeling that it is
inappropriate to do so (Hordern & Street, 2007a).

However, it is also important to note that some health professionals may be
using the MDT as a rationale for not raising sexuality, by positioning these
discussions as ‘someone else’s responsibility’. Given that a number of health
professionals may believe that “good professional practice involves practicing within
one’s area of knowledge and expertise” (Ussher, Perz, Gilbert, Wong, Mason, et al.,
2013, p. 1380), it may be that some health professionals avoid discussions of
sexuality because they do not position this area as part of their own, or their
professions’, skill set and area of ‘expertise’. This appeared to be the case in another
study, which found that some health professionals groups positioned sexuality as the
role of other professions (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). For
example, a physician in their study commented that psychologists would be best
placed to address sexual issues, as they are “looking at psychological issues, of
dealing with cancer” (p.1380). Of course, the problem that arises is that if health
professionals position discussions of sexuality as the role of others, sexuality may not
be raised at all, and consequently it is likely that the sexual and intimate needs of
many patients are going undetected and thus unaddressed.
The use of a ‘stepped skills’ approach, developed and proposed by deVocht and colleagues (2011), would be useful in optimising the likelihood of sexual concerns being identified and addressed by multidisciplinary teams. Within this complementary team approach, some health professionals would be designated the role of ‘spotters’, tasked with the role of identifying possible sexual issues, and where appropriate, providing referrals on to staff members who have the role of ‘skilled companions’. Skilled companions would then respond holistically to the sexual needs of patients, and provide specialist, person-orientated care. It would appear appropriate that ‘frontline’ medical staff be appointed the role of ‘spotters’, given their frequent contact with people with cancer. In particular, the provision of written information and checklists by medical staff to patients in order to identify, and disseminate information about, possible sexual changes, may enable better identification and subsequent referral of patients who require specialised assistance from allied health professionals (Blagbrough, 2010; Matzo, Ehiemua Pope, & Whalen, 2013; Ussher, Perz, & Gilbert, 2013).

In conclusion, having clear, designated roles and referral pathways within multi-disciplinary teams would be a useful strategy to ensure that patients are more likely to receive holistic treatment for sexual issues if they do not encounter all members of the multi-disciplinary team. Further, having clear, designated roles within health professional teams will likely also assist in positioning sexuality as an issue that all health professionals have some level of responsibility and role in addressing, and thus may assist in avoiding opportunities for health professionals to position sexuality as ‘somebody else’s responsibility’.
Differing Discursive Constructions of Care Settings: Sexuality in the Hospital, Hospice and Community Care Space

The second key issue in this chapter that emerged in the analysis of health professional accounts was the way in which the ‘space’ of the hospital, the hospice, and the community care setting was discursively constructed in markedly different ways in health professional accounts. Subsequently, it became evident that these different ‘spaces’ have varying effects on how people in palliative cancer care construct the experience of how they are able to express their sexuality across these different spaces. In essence, the hospital and hospice space was constructed in participant accounts as a space that was not conducive to providing or responding to the holistic needs of patients. Indeed, health professionals often used the following language to describe the hospital space: “factory-ness”; “depressing”; “facility”; “functional place”; “dehumanising”, “desexualising”; “depersonalising”; “disempowering” and “our territory”. The effect of this hospital space on the sexuality and intimacy of patients and their partners was constructed by health professionals as: “erodes the self”; “not a whole person”; “doesn’t promote closeness”; “soulful connection could be greatly compromised”, and “outside of their knowingness and their safety within which their intimacy might occur”.

In contrast, the community care space, where care is provided in the homes of people with cancer rather than in an institutional hospital or hospice setting, was described as: “a safe, sacred space”; “personal space”; “natural environment”; “privileged place”, and “their space”. Here people with cancer are in a space that is their own, over which they have control, and in which they are freer to express their intimacy. Furthermore, health professionals described themselves as “a guest” in patient’s homes, rather than patients being on “our turf” in a hospital setting. This
meant that the interactions and methods of establishing relationships with people with cancer in the community space were markedly different from those described in the hospital and hospice.

I will now provide a detailed discussion of the construction of these three care settings: beginning with the hospital and hospice settings, which will be discussed together under the headings ‘institutional care’, and lastly ending with a discussion of the community care setting.

**Institutionalised care: A depersonalising, desexualising, and disempowering space.**

In the accounts provided by the health professionals, it became evident that within a hospital “facility”, people with cancer occupied the subject position of ‘clinical object’; and consequently became “depersonalised”, “dehumanised”, and desexualised, which had implications for the experience and the expression of their sexuality within institutional settings. Linda, a psychologist working in a hospital, explains this experience:

I guess what I hear people talk about more when they’re in the end of their life is how the experience of being a patient almost desexualises people if they’re in a facility. You know, that sort of dehumanising would be too strong a word but certainly depersonalising and definitely desexualising.

The next three accounts illustrate how the material practices of the hospital produce the subject position of person with cancer as clinical object, whilst patients are staying in hospital care. Extending upon the patient experience of “depersonalisation”, Karen, a nurse, unpacks how the material practices of the hospital space result in patient’s “person” being “taken away…eroded”: 
And for anybody that’s got to go into a hospital. You’re told – even if you go in for something simplistic like a scan or an x-ray, you go in. You’re addressed often with a name that’s not familiar to you. You might be called something else. You’re told to put on a gown. But all of your person’s taken away. You just go in. You’re exposed. You know, it’s just – it’s – it’s eroded. It erodes yourself.

Further, Jean, a nurse, explains that because hospitals “run along the lines of what works best for the service provider”, decisions about service provisions are based on the needs of the service provider, rather than on the holistic needs of the patient. Consequently, Jean explains that patients do not have control over their routine, and thus it becomes harder for patients “to just be in their own place and maintain that sense of who they are”. Jean also notes that patients are “probably” more likely to have more control in a hospice setting than a hospital setting, though she notes that there are limited beds and time given to stay in hospice settings:

The patients are not at the centre of the decision making. So there needs to be a change I guess, a change in that a patient’s holistic needs are at the centre… they’re not at the centre of care. The cleaning is done at the time that suits the service provider. Taking of observations and things like that, it’s very often unnecessary, people are disturbed unnecessarily, and they’re not given enough time to just be in their own place and maintain that sense of who they are. And that includes being with their partner, being with people, just being on their own, and not being disturbed. They absolutely lose control over things, when they’re – particularly as an inpatient.

Jennifer, a palliative care physician, explains that there is no privacy and a “lack of respect for the patient’s personal space” in a hospital, highlighting that material
constraints, including a lack of resources, time, and staff, make it difficult for hospitals to “function” in a less “impersonal” way:

And the lack of respect for the patient’s personal space in a hospital, and even their privacy, like I had a lady who was a bit confused and so on and the other day the ward kept her door open but she kept taking all her clothes off, and you know really she needed someone to sit with her and either put her clothes back on or to keep the door shut but to have someone in there so she was safe and that sort of thing. But, the hospitals just can’t function, or they just don’t function like that, they don’t have the staff or the time or the resources or whatever so, they’re very kind of impersonal, and I think lots of patients just feel like they’re just a body in the bed to be sorted out, and to get out of there.

These accounts illustrate how the body of a person with cancer becomes constructed as a clinical object upon admission into the hospital, which consequently may limit patients’ capacity to practice their sexuality within these settings. Foucault (1975) argued that hospitals are arranged as an ‘examining apparatus’, which allows continual observation of the anatomical, sick body. Accordingly, within a hospital setting, and as was particularly evident in Jean’s account, patients lose control over their privacy and space, with hospitals operating within often inflexible routines that focus solely on the care of the physical body, yet do not promote care of emotional and relational forms of suffering. For the person with cancer, the impact of this lack of control over privacy can result in a ‘diminished self’, if, as Kathy Charmaz (1999) has argued, individuals establish their dignity on having control and autonomy. For example, in a study looking at dignity in an acute hospital setting, patients reported that losing control over privacy constitutes a threat to their dignity, whilst staff practices that provide control over privacy and interactions promote maintenance of
dignity (Baillie, 2009). This study highlights the importance of staff allowing opportunity for patients, where possible, to negotiate the amount of privacy they have in a hospital setting.

However, the provision of privacy for patients may be a fraught issue. Many health professionals I interviewed reported that most hospital staff they work with position patient expressions of sexuality as inappropriate within a hospital context. This suggests that health professionals may not be willing to provide the privacy required for patient expression of sexuality and intimacy. Indeed, many health professionals reported that hospital staff were often “confronted” and “horrified” by witnessing, or simply thinking about, patients and couples engaging in sexual expression in the hospital setting. This is an issue that Jennifer, a palliative care physician, talked about:

You know I have had horrified nurses when they’ve found an old man masturbating under the blankets at night, or you know, if there was anything other than a hand hold and a peck on the cheek as they left, I think the nurses, well I’m saying nurses because they would tend to see that kind of thing, they’re usually horrified by that. There’s certainly no appreciation of sexual needs in a hospital and you know if a young couple wanted to have sex in a hospital bed, God, there’s probably some protocol saying they should be shot or something you know, like it would be UNHEARD OF, and it would, you know, security would be called, and you know, the shock horror! [laughs]. Yeah, it’s [hospital] very unsupportive of people wanting to express themselves or, yeah it’s kind of like hand-holding’s okay, peck on the cheek goodbye’s okay, anything more than that would be, you’d be told off or something. It’s like a prison, that’s why everyone wants to get out so fast!
laughs]. I think the whole environment, the whole culture of, I mean I see hospitals are a little cultural city in their own right, and I think that whole cultural culture of hospitals is very anti-intimacy and definitely sort of anti-physical sexuality. Yeah.

In the above extract, Jennifer clearly highlights that whilst some forms of intimacy are acceptable to express in a hospital setting, such as a “hand holding” and “a peck on the cheek”, physical expressions of sexuality, in particular sex, are not at all supported. Jennifer also makes use of the metaphor of a “prison” to explain the “culture” of the hospital. By linking the hospital with a prison, she constructs the hospital as a regulated space, with consequences in place for the patients - or to continue using the analogy of the prison, ‘prisoners’ - if they transgress the rules of the hospital. Indeed, in her account, Jennifer links the act of a couple having sex in a hospital as essentially punishable by death, “there’s probably a protocol saying they should be shot…”, and in doing so, strongly emphasises the unacceptability of sex within a hospital setting. The use of the prison metaphor also serves to construct patients as having no agency within the hospital setting. In another account, Sabrina, a palliative care physician, explains how within a hospital setting, staff are happy to allow patients to close their door if they are “finding their visitors bothersome”. However, she explains that “we can’t do that” for couples, as it creates “unrest” for hospital staff, who imagine that couples may be engaging in sexual activities:

We are quite happy to keep a door closed if someone is finding their visitors bothersome, but if it was a couple and they said, “Can we keep the door closed?” It – like, like we can’t do that. It just causes a lot more unrest amongst the staff. I think we’ve had quite a number of people who were quite forthright in not even having a conversation but they would just keep the door
closed on a regular basis and no-one – you could just see the nursing staff thinking, “okay, I’ve got to give the MS Contin, what do I do? Do I knock, or do I just come back later, or do I wait ‘til the door’s open”, but no one wants to talk about it, you know, there is everyone’s imagination and should we be doing something to make sure that this is all kosher but it just causes everyone to be uncomfortable because this is not a way to, to have that sort of space when there is such a structure to a ward environment I think yet we are quite good at, you know, outdoor space or if someone says, “I just want to go for a walk”, that’s fine we give people space in other ways.

Beth, a nurse, also comments that staff would be “overwhelmed” if a couple wanted to engage in intimate practices such as “lie in the same bed”, and comments that this intimate practice is not permissible in a hospital:

Most [people with cancer/partners] will [raise concerns around sexuality and intimacy] at some stage when you’re speaking about the difficulties of long-term hospitalisation or those sorts of things. The expectations of caring staff are that you don’t do anything but hold somebody’s hand and that you actually don’t consider that there’s an opportunity to be able to – staff actually are often overwhelmed that somebody would want to lie in the same bed with people or do those sorts of things just to be next to them or close to them. They [health professionals] found that very difficult, because “don’t you know this is a hospital” and, you know, all those sorts of things.

In all of the above three accounts, the act of sex appears to be constructed as something salacious that couples ‘do’ within the hospital setting, with health professionals tasked with the role of “doing something to make sure that this is all kosher”. Accordingly, sexual expression or desire is not positioned as a normal part
of a patient’s or couples’ life, but rather something that needs to be contained and policed within a hospital setting. Indeed, in Beth’s account, health professionals seem to be positioned as having an authoritarian parenting role, ‘lecturing’ patients against expressing sexuality or intimacy, for, “don’t you know this is a hospital”? Therefore, it appears that unless patients or couples move outside of the hospital setting, to an “outdoor space”, there is no opportunity for couples to be granted space to express sexuality or intimacy, if expressing sexuality is something that they wish to do.

Yet, in all of the accounts above, there is evidence to suggest that some patients, and couples, have sought the opportunity for private space within the hospital setting to express intimacy and sexuality. This includes auto-eroticism, as referred to in Jennifer’s account, or simply lying on the bed together, as described in Beth’s account. Indeed, it is known that many palliative care patients have reported sexual activities to remain an important part of their quality of life (Lemieux et al., 2004). Nonetheless, these palliative care recipients have also reported that shared rooms and intrusion by staff have been barriers to expressing sexuality and intimacy within a hospital setting, pointing to the need for better facilitation of privacy for patients within hospital contexts. Further, given that some patients may not have the opportunity to return home, may not have access to private rooms; or, as Beth highlighted, may require long-term hospitalisation, the lack of privacy within a hospital is likely to be a particular problem for these patients and couples.

Regulation of sexuality and intimacy within the hospital: patients who self-police and limit their expression of sexuality and intimacy within the hospital.

As with many of the health professional accounts presented above, Andrea, a bereavement counsellor, reports that in a hospital setting, patients and couples are
“outside of their knowingness and their safety within which their intimacy might happen”. However, she also points out that sexuality and intimacy can be “shrunken…potentially annihilated, especially if you've got a couple who are doing the right thing within the system…who are very obliging of the system”. Sarah, a social worker, also highlights the expectation that patients conform to “the system” and routines of the hospital, and explains that patients are labelled as “difficult” or “uncooperative” if they do not:

It’s sort of like they [patients] are at the mercy of the staff and the system and it’s very difficult I think for them to say, “No” to anything. And if patients do say, “no”, to say like a test or a medicine or an interview, that they are sort of given a label as being difficult or uncooperative. So it’s quite a disempowering sort of experience I imagine and that’s what a lot of people have indicated.

As Sarah has pointed out, being labelled as “difficult” or “uncooperative” is certainly a disempowering experience for anyone. However, in the context of a health care setting, the effects of these labels are potentially even more powerful because patients are dependent on the hospital staff for care. As such, it appears that it would be quite difficult for patients and couples to resist the normative positioning of sexual expression as an unacceptable act within the hospital setting. But rather, as Andrea has pointed out, patients and couples may accept and practice in accordance with this normative positioning, and accordingly, may miss the opportunity to express and experience intimate contact. Indeed, Judy, a bereavement counsellor, recalls a bereaved partner she had worked with who had felt that it was not permissible to express intimacy in a hospital, and accordingly, was left experiencing “guilt” and “regret” because she had not responded to her partner’s request for intimacy:
I had a client recently who talked about – and it was very sad, it was very sad - talked about her husband had asked her to get into – to get on the bed with him when he was in hospital. And she said, “Oh, no, no, we’re not allowed to do that.” And when I asked her, I said, “did someone say to you that that wasn’t permissible?” And she said, “Oh, no, but we were in a hospital and so it wasn’t permissible.” When we unpacked it, it was the – when she was young, she can remember going to a hospital and the matron, or someone, coming in and saying, “Don’t lean on the bed like that, and don’t”, you know. There were these very strict – and sort of like slap on the wrist for, sort of for even looking close to the bed. So she reflected on that. But she actually had this great regret. She said, “I didn’t do the one thing that he asked me to do, and he always needed my – he always needed physical reassurance and I could have given him that and I didn’t”. So she was left holding that. And it was yeah, guilty, more than just regret; it was guilt, mmm.

Foucault's (1975) theorisations of surveillance and the panopticon are relevant here. Foucault used the metaphor of the panopticon to conceptualise how power can be maintained in institutional settings, including hospitals. Because institutions, such as hospitals, provide the possibility of constant observation, individuals may self-police their behaviour to ensure that they act in accordance with the normative discourses present in these settings. As such, Judy’s account is an apt illustration of how patients can adopt normative discourses that position expressions of sexuality and intimacy as unacceptable within a hospital setting, and by doing so, limit their expression of sexuality. What is central to point out here, is that whilst hospital staff may not explicitly convey to patients that sexuality and intimacy cannot be expressed in the hospital setting, this positioning may still be implicitly communicated through
the material practices of the hospital. For example, due to the lack of control patients have over privacy and space in the hospital setting.

**Hospice settings: An institutional setting more amenable to providing space for patient sexual expression and maintenance of patient identity?**

In my study, health professionals applied many of the same descriptions used to describe the hospital space, such as “depressing”, “desexualising” and “our territory, to the hospice space as well. This could be because the hospital and hospice setting are both institutional and “clinical” environments, and thus both retain some of the barriers to patient expression of sexuality and intimacy which relate to such an environment. This includes material constraints, such as lack of privacy and time, and discursive barriers, such as being an “unfamiliar” and “clinically driven” environment. However, the hospice space was also represented in health professional accounts as “a much gentler environment than an acute hospital”, and a space with a “far higher standard of accommodation and of care”, including, often, more single rooms than hospital settings. Thus, health professionals often reported that patients felt more “relief” and “peace” to be in a hospice setting, and found it a less “distressing experience” to be in a space that was not “focussed around acute medical care”. As Janine, a social worker reports:

> It [hospices] tries to be an in-between place. People are usually very happy to come. And they will often come from an acute hospital and they’re just so relieved to come to a place that’s not focussed around acute medical care. And we have – half our rooms are single rooms. So people often come from a shared room, to a single room so the peace and quiet they feel is, they can appreciate.
In the 1960s, the hospice movement sought to provide a more ‘homely’ space than the hospital setting, that would, in turn, promote the holistic and dignified care of dying patients (McGann, 2011). This included the recognition of the need for greater privacy, which in many hospice settings is offered through single rooms. Accordingly, the structure of the hospice, influenced by the palliative care discourse, provides a space in which patients are more likely to be able to maintain a sense of self and be more able to have opportunity to express sexuality.

Additionally, in the pursuit of developing a more ‘homely’ space for patients, the notion of ‘family atmosphere’ was also integral to hospice settings (McGann, 2011). Looking at previous research, it appears that hospices do succeed in providing a family-like atmosphere, with surviving partners of palliative care patients more likely to report that hospices were more ‘family-like’ and relaxed than the ‘very busy’ hospital environment (Seale & Kelly, 1997). Nonetheless, it is important to note that in my study, participants who worked from both hospital and hospice settings reported that many hospital staff did not support the expression of sexuality in both these settings. As such, in some ways, the structure of the hospice setting provides a better space than hospital settings for patients to maintain their sense of self and dignity, and to facilitate the continued expression of sexuality. However, it appears that for hospice settings to fully endorse and provide holistic and patient-centred care, the importance of expressing sexuality and intimacy within these settings to some patients and couples, also needs to be considered and better supported.
Supporting the expression of sexuality within institutional settings: A summary of barriers and possibilities.

As I have outlined, lack of control over privacy in institutional spaces was identified as problematic for patients. It negatively impacted on their dignity and capacity to maintain a sense of self, and diminished their ability to continue expressing sexuality and intimacy. Whilst staff may not be able to provide private rooms for patients, given the lack of availability of such facilities in many hospitals, it appears possible that they could facilitate negotiation around the amount of space and privacy that patients and couples have. For example, in Lemieux et al.’s (2004) study, when the palliative care recipients (who had reported that lack of privacy was a barrier to their expression of sexuality) were asked what could have been done differently they suggested that staff could have negotiated and advised them of times when they would be left undisturbed. Indeed, some health professionals in my study reported that they informed patients about the periods of time when they would be left undisturbed by staff – a strategy which reportedly allowed patients and couples space to express intimacy and sexuality if they desired. For example, Andrea, a bereavement counsellor (previously a nurse), spoke about needing to “de-institutionalise” the hospital setting in order to give patients space:

We’d have nice quiet music on, giving that particular patient in the [hospital name], giving her a massage. Her husband coming in, being really mindful of saying, “right, I won’t be back for this period of time, be it to do observations, be it to do your catheter”. That was working hard to de-institutionalise, to work within the boundaries in a way that still had them there, because they needed to be there for people’s safety and provide care. But not to become a barrier to a couple.
However it is also important to consider that although some health professionals may wish to support patient and couple expression of sexuality in hospital settings, they may not feel empowered to do so if they are concerned about the responses of colleagues, who, by contrast, feel that the hospital setting is not the place to express sexuality.

**Community care: “in their homes, they’re more who they are…it’s an equal encounter”**.

Health professionals who worked in the community described that the experience was “completely different” to working on a hospital ward as they were “always going as a guest into somebody’s home”, a contrast to the hospital and hospice environment, which was often referred to as “our territory”, and “our turf”. Andrea, a bereavement counsellor, speaking about her earlier role as a nurse, describes this intimacy of caring for people in their homes:

There’s something very intimate – full stop – around home nursing. Yeah, completely different [to working on a hospital ward]. It’s about home-based care in that you – I found I would work harder at maintaining boundaries. Whilst also being respectful, because I was in someone else’s home. But it was that family’s, that couple’s, that patient’s home. It’s like anything goes there for you; this is your safe, sacred space. I’m coming into that. This becomes an extension of my work environment. But this is their space.

Evident in Andrea’s account is the notion of ‘spatial vulnerability’ that can occur when health professionals operate in a home environment. Within the home care environment, health professionals can experience ‘vulnerability of closeness’, which can arise in “family-like relationships between nurses and patients” (Gilmour, 2006,
Accordingly, and as Andrea points out, health professionals need to work hard to maintain boundaries in the home environment.

Because the home environment was constructed as the patients’ “safe, sacred space”, these health professionals noted that conversations about sexuality arose more easily in the community care space, as patients were “more relaxed in their own homes” than in a “clinical ward environment”. For example, Janine, a social worker, explains that the process of building rapport and interacting with patients is different when visiting patients at home – a space where patients are not disempowered, and where there is a “richness” of “materials” reflecting “who they are”:

“...meeting people and working with people in a hospital setting which is just so not their natural environment. I find people love you to be in their home and then they can show you so much, you learn so much about them, often without words. It’s so much easier to build a relationship with them and it’s so rich because you’ve got all this material around the person when you meet the person in their own environment. I mean you’ve always got photographs and other cues. Whereas when you meet them in a hospital setting, it’s quite a different process of building a rapport and opening up an interaction. It’s more formal, they’re more on my turf. You know, they’re more disempowered, they’re most uncomfortable, and there’s so much of the interactions based around being in hospital and whether you’ll stay in hospital and whether you’ll go home or whether you’re going to die here and all those sort of things. So the cues for the whole interaction are different...”

Karen, a nurse, also describes how using the materials around the home can assist in building rapport and learning about the patient’s relationship. And, like Janine, her
account also demonstrates that health professional-patient interactions in the home are less clinically focussed than in a hospital setting:

You can go and you’ve never met this person but you can actually find a common ground before you start asking them clinical questions. There’s things that you can, you know, family pictures you can identify, things like – and how long they’ve been together and you can ask them when they met, all that sort of thing. So you get a – a feel for their relationship.

In the above accounts, home care is constructed as a space which challenges the health professional-patient relationship asymmetry, disempowerment, and unfamiliarity of the institutional space. Indeed, the above accounts concur with home care discourses which implicitly construct the home as a space that affords privacy, autonomy, and refuge from the ‘outside’ public space, thereby enabling individuals to express themselves and preserve their identities (Cristoforetti, Gennai, & Rodeschini, 2011; Exley & Allen, 2007). As the above accounts demonstrate, health professionals in my study also constructed the home as a “safe, sacred space” for patients where, surrounded by personal belongings, they could “maintain a sense of who they are”.

However, whilst health professionals acknowledged how the home environment might afford people with cancer greater privacy and familiarity to continue expressing their identity, it is important to acknowledge how the language used by these health professionals also reinforces, rather than challenges, asymmetrical patient-health professional relationships of power. Specifically, by drawing distinctions between the institutional space, “my turf”, and the home space, “your space”, the institutional space is implicitly reaffirmed as the domain of health professionals, and as such, means that patient agency within the institutional setting
may not be supported. Accordingly, these accounts also illustrate the need for critical thinking about how constructions of ownership of space can be challenged, in order to meet needs for increased patient agency within institutional settings.

**Home care: not always the ‘ideal’ for maintaining intimate relationships.**

The accounts I have presented have constructed home care as an improvement on the discursive and material constraints of institutional spaces - able to provide the privacy and familiarity central to constructing a sense of self and to promote intimate practices. It is, however, important to note that at times, the provision of care in the home can also have the potential to compromise the intimate relationship of the patient and their partner.

In home care, intimate partners and family members are responsible for providing much of the care of the patient (Exley & Allen, 2007). As the person with cancer’s ability to care for themselves diminishes, the intimate partner or family members can have additional responsibility of providing care of the body, including, caring for an ‘unbounded’, leaky adult body (Cartier, 2003; Lawton, 1998). Within an institutional setting, this level of ‘bodywork’, caring for the body, would be predominately undertaken by health care professionals, but when this care is carried out by intimate partners, intimate sexual relationships can be compromised (Taylor, 2015). For example, in one study, the accounts of partner carers illustrated how the person with cancer can be re-positioned as childlike or an asexual sick patient, leading to sexual relationships being diminished (Gilbert et al., 2009). Further, in another study (Exley & Allen, 2007), one carer spoke about the distressing and difficult nature of providing such intimate care for their incontinent partner, explaining to the researcher that the nature of the caring role had “somehow destroyed the previous sexually intimate relationship she had had with her husband”
(p. 2323). However, this carer went on to speak about the impact of no longer being responsible for their partner’s care following his admission into hospital, which, despite the hospital being experienced by them both as “an alien environment” (p.2323), had restored “their identities as partners” (p. 2323). Therefore, although the institutional setting does not afford the same level of privacy and familiarity as the home setting, the care that it provides – in particular, bodily care - can also be central to maintaining intimate sexual relationships.

Finally, it is also important to recognise the ways in which bringing in hospital equipment into the home can change the ‘meaning’ of the home space and accordingly can impact couples’ intimate relationships. As patients in other studies have reported, the addition of assistive equipment into the home, in particular, a hospital bed, can challenge the ‘togetherness’ of the couple, by reducing opportunities for touch and other physical contact (Bowden & Bliss, 2008; Taylor, 2011). Further, couples have also reported in previous research that the addition of assistive equipment into the home also signals to them the reality of the deterioration of the patient’s condition and the patient’s approaching death (Taylor, 2011) – a difficult emotional experience for some couples as I discussed in detail in Chapter Four. As such, the authors of both these studies argued that health professionals providing care in the community need to be aware of the impact that bringing in hospital equipment to the home can have on intimate relationships.

In conclusion, the community care space can provide insight into how care, and maintenance and expression of patient sexuality, might be better provided in institutional settings. This includes, within the material constraints of institutional settings, greater negotiation of privacy and communication about when space can be provided, and person-orientated communication. Further, I have also highlighted
how by distinguishing between institutional settings as “our turf”, and community care as “their space”, health professionals implicitly reinforce the power asymmetry present in institutional settings, which means that health professionals may be less willing to provide a more holistic approach to care in institutional settings. Lastly, as I have outlined, community care is not always the ideal space for care to be provided for some patients and couples. Therefore, health professionals could consider how the provision of hospital equipment into the home may represent losses for the patient and family members, and may also disrupt intimate relationships.

Conclusion

In this chapter, I demonstrated that the material limitations of clinical settings reportedly functioned to limit the discursive positions that could be taken up by the participants in relation to sexuality. In particular, it was found that the biomedical discourse shaped the materiality of clinical settings in a way in which the focus of care is on the diseased body. The particular material constraints which worked to prevent participants from recognising patients’ and couples’ sexual needs, and from supporting expressions of sexuality within clinical settings, included a lack of privacy, and consult time which was primarily allocated towards care and treatment of the physical body. However, some participants did report that a few of these material constraints were lesser in hospice settings, with, for example, more single rooms provided in hospice settings. Likewise, some participants who worked in both hospital and hospice settings reported ways in which they were able to manage some of these material constraints at times. This included informing patients or couples of times when they would be left uninterrupted by staff, and by providing written information about sexual changes when they had limited consult time available.
However, whilst the material limitations of institutional settings reportedly placed limits on the discursive positions that participants could take up, participants could also draw on the biomedical discourse, and the material constraints of clinical settings, to take up subject positions that legitimated any avoidance of addressing sexuality. For example, participants had opportunity to draw on the subject position of the ‘busy’ and ‘important’ health professional, who has no time to respond to the emotional and relational sexual needs of patients. Medically trained participants, in particular, were also constrained by the biomedical discourse within which they were trained, which constructs the emotional and relational aspects of sexuality as outside of their professional role and area of expertise (Byers, 2011; White et al., 2013). However, these participants may have also had opportunity to use these limitations of their training to take up the subject position of the ‘expert’ health professional, who must only practice within their area of expertise. What is important to note, however, is that if health professionals adopt either of these subject positions, they have opportunity to excuse any avoidance of broaching sexuality – a topic which they may feel uncomfortable discussing, given the broader social construction of sexuality as taboo and private (Nyatanga, 2012).

Similarly, the construction of sexuality as private and taboo may have contributed to the ‘fear of sexuality’ within clinical settings, which was evident in participant accounts; with the practice of sexual activities by patients or couples in hospital settings constructed as salacious, and as needing to be policed and limited by health professionals. Further, as a few participants accounts highlighted, patients and partners may also self-police their own expression of sexuality within these settings. This is perhaps because they perceive that staff will not welcome their attempts to practice sexuality or intimacy - even if it is not explicitly disallowed by staff - and
also because the lack of privacy within hospital settings limits expressions of sexuality. Finally, this analysis also drew attention to how the language that participants’ used to construct the institutional settings, “our turf”, and community space settings, “their space”, can actively work to reinforce the existing power asymmetry between these spaces. Thus, this language may hinder the capacity of health professionals to practice in a more holistic and patient-centred way, which may include seeking ways to support patients and couples to express their sexuality and intimacy within institutional settings if patients and couples wish to.

In summary, the analysis presented in this chapter demonstrates that it is important to examine how the material limitations of clinical settings and of medical-health professionals’ training – as they are shaped primarily by the biomedical model of health care – places constraints on the capacity of health professionals to address the sexual and intimate concerns of palliative patients and partners. Likewise, I also argued the importance of examining the subject positions that the biomedical discourse opens up for health professionals, and how adoption of these subject positions may allow them to excuse any avoidance of addressing sexuality. Health professionals’ use of language to describe the ownership of health care settings, as well as to describe the expression of sexuality within health care settings, can also work to re-inforce existing constructions which position clinical settings as not the appropriate place for patients to express sexuality or intimacy. Similarly, whilst health professionals may not have power to change some material constraints present within clinical settings, some participant accounts demonstrated that when the patient’s sexuality and sexual expression within clinical settings was positioned as important, some were able to work within the material constraints of these settings to support these requirements.
Chapter Seven: Conclusions

This thesis looked at how palliative care health professionals communicate about, and respond to, the sexual and intimate needs of palliative patients and their partners. In particular, this thesis explored how palliative care health professionals may negotiate material, discursive and intrapsychic factors which may either enhance or constrain their capacity for sexual communication and practice. During the analysis chapters, I discussed and outlined the implications of the findings of this thesis in relation to previous research and theory. As such, this conclusion chapter will move on to focus on the implications of the research presented in this thesis for health professional practice. This chapter will also include an overview of the limitations of this study, and will provide suggestions for future research. I will then conclude this chapter by providing my overall reflections on doing this research.

Implications for Practice

In the present study, the majority of the participants acknowledged that sexuality and intimacy were important aspects of their palliative patient’s and partner’s lives. They were also able to identify a broad array of physical, psychological, and relational post-cancer changes that impacted the sexual wellbeing and relationships of palliative patients and their partners, in line with recent research which has examined health professional sexual communication in the context of cancer (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Correspondingly, some participants explained the strategies that they used to address the sexual and intimate concerns of patients and partners. These strategies primarily centred on strengthening intimacy between couples, which included facilitating relational communication and supporting the expression of non-sexual intimate practices. In contrast, talking with palliative patients and their partners about how cancer and cancer treatments had
impacted on their sexuality, and in particular how it had impacted on their sexual practices, appeared for many participants to be a difficult and uncomfortable topic to broach and discuss. This likely reflects the broader cultural construction of sexuality as a private and taboo topic (Stead et al., 2003). Additionally, however, it was also found that participants were not always able to recognise or respond to the sexual and intimate needs of patients due to a range of other material, intrapsychic and discursive factors. As such, the findings of this study suggest that interventions aimed at improving palliative care health professional sexual communication would benefit from addressing the material, discursive and intrapsychic barriers that can limit sexual communication, as I will now go on to discuss.

In Chapter Five, it was identified that normative discourses around age, sexuality, illness and dying contributed to the participants positioning sex as irrelevant or inappropriate for some palliative patients. For example, health professionals who drew on ageist discourses and the construction of sex as coital sex positioned older patients as too frail for sex, as well as uninterested in and offended by discussions of sex. Likewise, constructions of sex as performance and as coital sex contributed to sex being positioned as irrelevant for some palliative patients who were deemed too unwell for coital sex. Further, the male sex drive discourse (Hollway, 1984b; Ussher, 1997) also led to men being positioned by participants as having greater sexual desire and needs than women, meaning that the sexual needs of women tended to be overlooked. Thus, these findings demonstrated that normative discourses of heterosex, gender and age can constrain the ability of health professionals to recognise the needs of particular patient groups. As a result, these patient groups are less likely to receive information or support about any sexual concerns they may have; as previous research has also found (e.g. Gott, Galena, et
Further, the language that some health professionals employed at times also worked to reinforce normative discourses that positioned sex as irrelevant or inappropriate for certain patient groups. For example, the use of the terms “oldies” and “elderly” by some professionals functioned to position older patients as asexual, easily offended by discussions of sex, and too 'frail' to participate in sexual activities - thereby reproducing ageist discourses (Nussbaum et al., 2005) and constructions of sex as performance (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Discourses of heterosexuality were also reportedly upheld on an institutional level in some health care settings (Johnson et al., 2004), with patient documentation referring to ‘husband’ and ‘wife’ rather than using neutral language such as ‘partner’. As such, this thesis and the findings of previous research (e.g. Hordern & Street, 2007b; White et al., 2013) add support to the need for interventions that are aimed at improving health professional sexual communication to consider the role of these normative discourses and language in limiting palliative care health professionals’ recognition of the sexual needs of particular patient groups.

In this vein, providing palliative care health professionals with information on the possible physical, embodied, and relational needs of palliative patients and partners would both increase knowledge, as well as assist in challenging the social myths that position sex as irrelevant or inappropriate for particular patient groups. Further, informing palliative care health professionals that patients and their partners will tend not to raise issues of sexuality due to feelings of embarrassment, shame, or feeling as though it is inappropriate to do so (Hordern & Street, 2007a), will also help establish that it is important for health professionals to initiate discussions of sexuality.
The findings of this thesis also reaffirm the importance of palliative care health professionals having a broad conceptualisation of sex. This would involve challenging normative and hegemonic medical and sociocultural discourses that position 'real' sex as coital sex that occurs within heterosexual relationships, with other forms of sexual expression considered supplementary or secondary (McClelland, 2015; McPhillips et al., 2001; Ussher, Perz, Gilbert, Wong, & Hobbs, 2013). This could be achieved by health professionals legitimising and supporting alternative sexual discourses to the coital imperative, by positioning non-coital sexual practices, such as massage, hugging, kissing, oral sex, and masturbation as an equally legitimate component of sex (Ussher, Perz, & Gilbert, 2015; Wittmann et al., 2015). This conceptualisation of sex would assist in enabling palliative health professionals to both consider and legitimise the sexual needs of non-heterosexual and single patients, who are currently overlooked patient groups within health services (Filiault et al., 2008; Tindle et al., 2009). Acknowledging the legitimacy and importance of non-coital practices may also allow health professionals to consider their role in assisting the renegotiation of the sexual practices of palliative patients and partners, for whom post-cancer coital sex may be either difficult or undesired, through suggesting possibilities for non-coital forms of sex (McClelland et al., 2015; Nyatanga, 2012). Assisting heterosexual couples to challenge the coital imperative has been identified as a particularly important intervention considering some couples may refrain from all sexual and intimate practices due to their belief that engaging in non-coital practices will inevitably lead to coital sex (Gilbert et al., 2010a; Rossen et al., 2012). Indeed, it has been found that giving patients and partners a self-help guide or a one-off consultation with a health professional, where both provide information on non-coital sexual practices, is often effective in assisting couples to
legitimise and explore non-coital and intimate practices (Dieperink et al., 2015; Perz et al., 2015; Wittmann et al., 2013).

In relation to the format of interventions to improve health professional communication about sex, there is evidence that brief educational and experiential workshops are effective. Specifically, workshops in which health professionals are educated on the sexual needs of cancer patients, provided with specific strategies on how to broach sexuality, and then given opportunity to practice and receive feedback on their sexual communication skills, have been found effective in improving sexual communication (Hordern et al., 2009; Maguire & Piteathly, 2002; Rosen et al., 2006). In particular, these workshops have been found to increase health professionals' knowledge of the sexual concerns that patients and partners may experience, challenge sexual myths, and increase health professionals' confidence and resolve to raise sexual issues in their practice (Hordern et al., 2009; Rosen et al., 2006). As such, these workshops appear to be an effective way to mitigate some of the discursive and intrapsychic barriers, such as the adoption of sexual myths and lack of confidence and knowledge; that can limit palliative care health professional communication about sexuality (Hautamäki et al., 2007; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Further to this, and given the findings of this thesis, I suggest that it would also be helpful for training workshops to provide information to palliative care health professionals on how their use of language can also shape whether particular palliative patient groups are positioned as having sexual needs.

In addition to workshops, there are a number of written guidelines and sexual communication models available which may also assist palliative care health professionals to better understand and respond to the sexual concerns of palliative patients and partners. Firstly, in relation to written guidelines, these provide specific
strategies on how health professionals can raise sexuality within the context of cancer (e.g. Brandenburg & Bitzer, 2009; National Health and Medical Research Council, 2003; Stausmire, 2004), and several also provide information about the potential sexual needs of cancer patients and their partners within a palliative context (e.g. Cagle & Bolte, 2009; Hordern & Currow, 2003). A few of these guidelines also challenge social myths that may prevent sexual communication, such as the notion that older patients are uninterested in sex (e.g. Hordern & Currow, 2003; Katz, 2005). However, existing or future guidelines for addressing sexuality in palliative care could be extended to include information about the sexual issues that were identified in the present study, which are currently not included in existing guidelines. These sexual issues include the potential impact of anticipatory grief and advanced bodily deterioration in contributing to withdrawal from sexuality and relationships, as well as challenging the assumption that advanced cancer patients are too unwell to engage in sexual practices.

In relation to sexual communication models, the PLISSIT model (Annon, 1981) has been widely endorsed as a framework for supporting health professionals to assess and manage the sexual concerns of patients and partners (Hughes, 2000; Stausmire, 2004), and has four intervention levels: ‘Permission’, ‘Limited Information’, Specific Suggestions’ and ‘Intensive Therapy’. In the ‘Permission’ level, palliative care health professionals can normalise and provide opportunity for patients or partners to discuss post-cancer sexual concerns. Next, in the ‘Limited Information’ level, health professionals can provide information on sexual changes, dispel sexual myths, and explore sexual changes that the patient or partner may be experiencing. As part of this stage, health professionals can offer written information to patients and partners on post-cancer sexual changes (Ussher, Perz, & Gilbert,
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2013). For example, there are a number of sexuality, fertility and cancer self-help guides (e.g. BCNA, 2011; Cancer and Sexuality Team, 2011) which health professionals could provide to patients. As it has been found that some patients or partners may prefer written information to a consultation session about sexual changes (Cowan & Hoskins, 2007; Ussher, Perz, & Gilbert, 2013), it seems that it would be beneficial for health professionals to provide patients and partners with the option of receiving information about sexual changes in either or both formats (Perz et al., 2015). In the third stage, health professionals can provide patients and partners with ‘specific strategies’ to manage sexual changes, with referrals to specialist services or health professionals provided in the fourth intervention level, “Intensive Therapy”. Previous cancer and sexuality research has demonstrated the efficacy of both the early and late stages of the PLISSIT model; particularly when information and interventions to improve sexual wellbeing include partners as well as patients (Perz et al., 2015; Taylor, Harley, Ziegler, Brown, & Velikova, 2011).

In addition to normative discourses of heterosex, gender and age being found to limit participants’ sexual communication, I also identified that participants were constrained by the biomedical discourse, which emphasises care of the physical, sick body rather than the psychosocial aspects of patient care (Foucault, 1963, 1975). As I argued, the biomedical discourse predominantly shapes the training that medical health professionals receive (Frankel, 1995; Shapiro, 2011), as well as the structure of clinical settings. These constraints reportedly included medically-trained health professionals being largely focussed on responding to 'clinical' issues to the exclusion of sexuality; physicians and nurses lacking consult time to respond to the 'non-medical' sexual and intimate concerns of patients; and palliative care physicians having difficulty in responding to the sexual needs of patients that diverged from
sexual functioning. These are all barriers to sexual communication which have been reported by health professionals in previous research (e.g. Carr, 2007; Hordern & Street, 2007a; Ong et al., 2000; Oskay et al., 2014).

In light of these findings, the inclusion of communication skills and sexuality training in medical and nursing undergraduate and postgraduate education programs would assist in providing broader cultural support within medicine that addressing sexuality is part of the medical role, as previous researchers have suggested (Hordern & Street, 2007a; Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Time constraints within clinical settings also need to be improved, although it is important to acknowledge that this may be difficult to achieve in some palliative care settings. For example, health services (including palliative care services) in rural communities have reported inadequate staff levels and allied health services, leading to work overload on existing staff (Weinhold & Gurtner, 2014). As such, palliative care health professionals in these situations may face additional challenges in overcoming time constraints as a barrier to sexual communication, as they must prioritise and respond to multiple patient health needs within limited time frames.

Further, and as has been found in other research, both the lack of privacy and the focus on the physical body within clinical settings reportedly contributed to the desexualisation of the patient's body (White et al., 2013), and potentially eroded the identity and selfhood of some patients (Baillie, 2009). It also meant that patient sexual and intimate expression within clinical settings was reportedly deemed 'risky' by palliative care health professionals, as well as by palliative patients and their partners (Lemieux et al., 2004). In addition, the language some participants in the present study used functioned to position sexual expression, or the discussion of sexual needs, as inappropriate and not a priority within clinical settings. For
example, sexual expression within hospital settings was often described as a salacious act that needed to be policed by health professionals, with the use of prison metaphors reinforcing the hospital as a space where patients lack agency. Similarly, hierarchical health professional-patient power differences within hospital settings were also sustained through the description of the hospital as the “turf” of health professionals, and the home as the domain of patients. In contrast to the representation of the hospital as a space where sexuality was not supported, the home was represented as a space where the health professional-patient hierarchy was disrupted, and where patients were able to better maintain their identity and intimate relationships.

Thus, these findings suggest that there is a need to consider how clinical settings may be discursively reconstituted to better meet the sexuality needs of patients and partners, through becoming more ‘home-like’ (Gilmour, 2006; Malpas, 2003). This discursive reconstitution would involve health care settings, at an organisational and individual health professional level, to work towards privileging and supporting patient privacy and patient self- and sexual-expression. Questions which could be considered by both management staff and palliative care health professional teams within hospital settings to facilitate this include: ‘How do patients and partners experience their stay in the hospital?’ ‘How can sexual and intimate expression be better supported by us in clinical settings?’ and ‘How can patient self-identity and privacy be better supported in clinical settings?’ Health professionals could also be encouraged to reflect on how the language that they may use to describe health care settings can sustain the hierarchical health professional-patient power differences that can limit sexual communication and patient sexual expression within clinical settings.
The findings of this thesis highlighted that when palliative care health professional teams privileged patient sexuality and privacy they were able to find ways to support this. For example, this included health professionals: knocking on the door to the patient’s room before entering; telling patients or couples when they would be left undisturbed by the health professional team; and encouraging couples to lie on the bed together. Further, person-centred initiatives, such as encouraging patients and families to bring in photographs or other personal items, can also assist in bringing the patient’s identity into focus, and may also help health professionals to engage differently with patients (Taylor & Chadwick, 2015). Indeed, as the findings of this thesis illustrated, health professionals who worked in both community and hospital settings reported that it was easier to build rapport and trust with patients in their home, which made it easier to broach sexuality with patients. Supporting patient privacy, identity, and sexual expression within hospital and hospice settings would assist in making the hospital settings a less distressing place for patients and partners, and would assist in the maintenance of patient dignity and intimate relationships (Baillie, 2009; Lemieux et al., 2004).

Another issue that was highlighted in this thesis was the importance of recognising that particular structural and discursive barriers are not necessarily the same or present across all clinical settings in which palliative care is provided. As such, different palliative care health professional teams will need to recognise and negotiate the particular barriers that are present within the particular clinical setting that they work in. In this vein, I suggest that it is important for sexual communication interventions to facilitate a team approach to addressing sexuality, as this would help ensure that all members of the palliative care health professional team consider sexuality as an important issue to address with palliative patients and their partners,
and that sexual communication is on the team agenda (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Interventions that occur on the level of palliative health care settings could include establishing responsibility within teams for who raises sexuality with patients, and who might be able to provide specialised help. This approach would assist in reducing the diffusion of responsibility within teams, and would also assist in making use of the diverse skill sets inherent within multidisciplinary teams (de Vocht et al., 2011; Jenkins et al., 2001). Putting sexual communication on the palliative care team agenda would also help alleviate the concerns of any health professionals who may be reluctant to address sexuality due to concerns that their colleagues would find such practice inappropriate; a concern that has been reported in my study and in previous research (Hordern & Street, 2007a). Further, palliative care health professional teams would also benefit from having an open discussion about the structural constraints of the particular settings that they work in which may limit sexual communication and patient sexual expression, and considering ways in which some of these structural barriers might be able to be overcome or mitigated. For example, this may include establishing staff protocols where patients are told when they will be left undisturbed by members of the health professional team.

Finally, at the beginning of this thesis I argued that whilst structural and discursive factors may constrain health professional sexual communication, they may also be able to actively negotiate the subject positions made available by these discourses and the material constraints of clinical settings to justify particular practices in relation to sexual communication (Foucault, 1976; Stenner, 1993). Indeed, a key finding of this study was that there were a number of available subject positions that health professionals could draw on to exonerate themselves from
addressing sexuality, whilst also positioning themselves as acting in the best interests of the patients. For example, it was identified that health professionals could position themselves as considerate and sensitive health professionals for not raising sexuality, through positioning older patients as easily offended by discussions of sexuality, or by drawing attention to the lack of privacy and time within clinical settings that make sexual conversations difficult (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). Similarly, through drawing on the subject position of the ‘expert’ health professional, made available through the biomedical discourse, health professionals could justify avoidance of raising sexuality, because ‘good’ health professionals do not practice outside of their expertise (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013). However, as I argued, sexuality may actually be avoided due to health professional discomfort, given the broader construction of sexuality as ‘taboo’ and ‘private’ (Stead et al., 2003).

Whilst these contextual and discursive barriers can and do exist, when health professionals adopt these subject positions it means that they are potentially less likely to adopt a position of agency, and therefore seek out ways in which some of these barriers may be challenged or mitigated. Yet some participants in this study, who adopted a positioning of agency in relation to sexual communication, described ways in which some of these barriers could be mitigated. For example, this included routinely raising sexuality with patients, or by creating space for patient expressions of sexuality in clinical settings. As such, sexual communication interventions that challenge social myths, that support a team approach to addressing sexuality, and that build the perceived confidence and skills sets of health professionals to address sexuality will also assist in undermining the subject positions that health
professionals can take up to justify their avoidance of raising sexuality (Ussher, Perz, Gilbert, Wong, Mason, et al., 2013).

**Strengths and Limitations, and Implications for Future Research**

A number of strengths and limitations were identified in relation to the research reported in this thesis. Accordingly, in this section I will first look at the strengths of the material-discursive-intrapsychic approach in the case of this research. I will then outline how future research may be informed by the identified limitations of this study, and I will also discuss how some of the findings of this study may be used as a platform from which to inform future research.

At the outset of this thesis, I argued that socio-cultural and medical discourses may interact with personal and structural barriers to shape whether or how health professionals communicate about sexuality, and are therefore worthy of consideration. However, I noted that much of the existing literature to date has not considered the role of discursive constructions, along with personal and structural barriers, in enabling or constraining health professional sexual communication and practice. Rather, much of the existing research in this area has studied the personal and structural barriers to sexual communication, such as the lack of training and privacy constraints in clinical settings. Accordingly, a particular strength of this thesis was the adoption of a material-discursive-intrapsychic theoretical framework, which allowed for an examination of how constructions of sexuality, aging, medicine, illness and dying can shape the materiality of clinical settings, as well as palliative care health professionals’ understandings of palliative patients’ and partners’ post-cancer sexual wellbeing. Likewise, this theoretical framework also allowed for an examination of how the material constructions of clinical settings can
shape the discursive practices and intrapsychic experiences of health professionals in relation to sexual communication.

I now turn to the discussion of identified limitations of this study, and my suggestions for future research. Firstly, no research to date, including the present study, has explored how occupational therapists and physiotherapists may address sexuality in the context of cancer and palliative care. However, it has been suggested that these two health professional groups may play a more practical role in addressing sexuality. For example, occupational therapists may play a useful role in assisting patients and partners to negotiate the impact of assistive equipment, such as hospital beds and medical equipment in the home, which has been reported by some patients as a barrier to sexual expression (Bowden & Bliss, 2008, 2009; Taylor, 2011). Physiotherapists, on the other hand, may be able to use exercise therapy to improve the movement and functioning of the body for various sexual practices (Levack, 2014). Thus, future research could examine how occupational therapists and physiotherapists position their role in relation to addressing sexuality in the context of palliative care, and whether they are able to provide unique interventions to improve the sexual wellbeing of palliative patients and their partners.

Secondly, health professionals in this study raised particular sexual concerns of patients and partners that have either not been identified or empirically explored in the existing cancer, palliative care and sexuality literature. Likewise, other researchers have also recently drawn attention to the need for further research to be conducted in these areas. These sexual concerns include how sexual violence and consent is experienced and addressed in palliative care (Jayawardenena & Liao, 2006), and how experiences of either renewed intimacy or the loss of intimacy and sexuality may shape partners’ bereavement experiences (Taylor, 2014). In this thesis I also
commented on the dearth of research which has explored the sexual needs of un-partnered and non-heterosexual palliative patients and partners, an oversight which has also been reported by other researchers (Brown & Tracy, 2008; Hordern, 2008; McClelland, 2015; Perz et al., 2013). As such, further research is needed to explore these potential concerns from the perspective of palliative patients and partners (including bereaved partners), as well as to gain greater understanding of the support and resources that patients and partners may require from palliative care health professionals and health services.

Thirdly, during some of the interviews, it appeared as though some health professionals became reflexive about how they were positioning particular patient groups as asexual or not interested in sex. Similarly, following some of the interviews I conducted with health professionals, a number of health professionals contacted me to say that the interview had allowed them to reflect on their usual sexual communication practices, and that consequently they were intending to change their sexual communication practices. For example, some participants mentioned that participating in the interview had reportedly helped them realise that they had been making assumptions about particular patient groups, such as the assumption that older or single patients had no sexual concerns, and so consequently they had resolved to begin asking these patient groups about their sexual needs.

These experiences led me to consider, as other researchers have argued and found (Koelsch, 2013; Ortiz, 2001), that the interview process itself can change participants’ subjective experiences and understandings of events, and can allow participants’ to gain self-knowledge. As such, I suggest that it would be worthwhile for future sexuality and cancer research with health professionals to conduct a second interview, perhaps a few weeks after the first interview. This second interview could
explore whether and how the health professionals’ first interview experience may have changed their understandings of, or practice, relating to palliative care sexual communication. This may also have implications in terms of interventions to improve health professional sexual communication. In other words, allowing health professionals to talk about and reflect on their experiences of sexual communication with an interviewer may be one avenue through which health professionals can become self-aware of, and therefore challenge, the dominant discourses that they may be un-reflexively adopting in their practice (Foucault 1976). However, whilst these health professionals reported positive changes in how they intended to practice sexual communication following the interview, it is also possible that for others it had the opposite effect. That is to say, their participation in the interview may have reinforced some of the problematic ways in which they positioned particular patient groups as asexual, and how uncomfortable they felt about communicating about sexuality. As such, for health professionals who remain unconfident or uncomfortable in addressing sexuality following a second interview, they could be offered information about sexual communication workshops to address these concerns.

Finally, I suggest that further research could explore how discursive and structural barriers may be managed across various palliative health care settings. For example, given the findings of this thesis suggested that sexuality is raised and addressed differently across community and hospital settings, individual interviews with patients and health professionals could further explore whether health professionals may build rapport and broach sexuality differently in patient’s homes in comparison with hospital settings. Further, interviews with health professionals could also explore how structural barriers, such as the lack of privacy in clinical
settings, may be managed across different hospitals and hospices. Similarly, research could also explore whether particular health care settings have employed particular initiatives to support patient sexual and intimate expression within those settings, and patients’ and partners’ experiences of these initiatives. The outcome of this research may be able to identify successful initiatives that can support patient sexual and intimate expression and relationships within clinical settings. It may also be able to provide further elucidation on how the different spaces in which palliative care is provided might shape how sexuality is raised and addressed by health professionals.

**Final Reflections**

In doing this thesis, what I found striking was how little research has been conducted in the area of palliative care and sexuality, and particularly in the area of sexual violence in palliative care. Even in a palliative care context which is centred on addressing the needs of the ‘whole’ person, and is breaking down the taboo of talking about death and dying, the topic of sexuality appears to remain taboo. However, the findings of this thesis and my interactions with other palliative care health professionals have highlighted for me that many consider sexuality and intimacy to be an important part of the quality of life of patients and their partners, and an area that they wish to better address. It is my hope that this research will contribute to knowledge around the sexual and intimate issues that palliative patients and partners may experience, and how palliative care health professionals may be able to better respond to these needs.

As I noted earlier in this thesis, I am not a palliative care health professional. I therefore came into doing this research without any firsthand experience of knowing what it is like to be confronted with the sexual and intimate issues of patients, or of the potential challenges of responding to these issues in practice;
including direct experience of the time pressures that health professionals may face in clinical settings.

As such, throughout this research, I endeavoured to be mindful and empathetic to the factors that can make sexual communication and practice difficult. For example, I recognise that health professionals may be vicariously impacted by the stories that they hear from patients, and may feel inadequate or distressed themselves if they are unable to relieve the suffering of patients as they relate to sexuality and intimacy. Similarly, I also understand that some palliative patients and partners may also place health professionals in a position where they are expected to provide ‘answers’ or relief to their suffering – even when health professionals may be unable to provide such support. However, I have also reflected that not being a health professional may have made it easier for me to be in a position to identify the subject positions opened up by the health professional role that can be used to justify any avoidance of sexual communication.

Nonetheless, overall, the findings of this research led me to appreciate that palliative health professionals must often negotiate a variety of structural, personal and discursive factors on a case-by-case basis, and may face ethical dilemmas. Sexuality, therefore, can be a difficult and complex issue to address at times.

Concluding Remarks

This thesis examined health professionals’ communication and practice around sexuality and intimacy in the context of cancer and palliative care. To extend the current body of cancer and sexuality research, thirty health care professionals who work with palliative patients and/or their partners, comprising physicians, nurses, social workers, psychologists, counsellors and bereavement counsellors, were interviewed. The findings of this thesis demonstrated that palliative care health
professionals have a broad understanding of the physical, psychological and relational sexual and intimate needs of palliative care patients and their partners.

However, this thesis also identified a range of discursive, material and intrapsychic barriers which limited the ability of health professionals to recognise and respond to the sexual and intimate needs of patients. Therefore, the findings of this thesis suggest that future research and strategies to improve health professional sexual communication and practice also need to focus on acknowledging and challenging some of the dominant discourses around sexuality, gender, age, dying and illness that both shape the materiality of clinical settings, and health professionals’ understandings of the sexual and intimate needs of patients and their partners.
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Appendix 1: Statement of Ethics Approval

UWS HUMAN RESEARCH ETHICS COMMITTEE

14 December 2011

Doctor Emilee Gilbert,
School of Psychology

Dear Emilee and Lauren,

I wish to formally advise you that the Human Research Ethics Committee has approved your research proposal H9397 “Talking about sexuality and intimacy: Health professional communication in the context of palliative cancer”, until 30 September 2014 with the provision of a progress report annually and a final report on completion.

Please quote the project number and title as indicated above on all correspondence related to this project.

This protocol covers the following researchers:

Emilee Gilbert, Jane Ussher, Lauren Kadwell.

Yours sincerely

Dr Anne Abraham
Chair, UWS Human Research Ethics Committee

e.gilbert@uws.edu.au
16314229@student.uws.edu.au
Appendix 2: Flyer

University of Western Sydney
Centre for Health Research
School of Medicine
Locked Bag 1797
Penrith 2751 NSW Australia

Cancer and Sexuality Study
Volunteers Wanted:
Health professionals who work with people with cancer who are receiving palliative care and/or their partners.

The purpose of the study: To explore how health professionals communicate with patients and/or their partners about sexuality and intimacy in a palliative oncology context. The aim of this research is to explore how health professionals view sexuality and intimacy in the context of palliative care, and their experiences of discussing sexuality and intimacy with patients and/or their partners.

Who can take part? Health professionals who have had experience working with palliative care patients who have cancer and/or their partners. This can include doctors, psychologists, counsellors (including bereavement counsellors), social workers and nurses.

What is required? You can choose to participate in either an individual interview or in a focus group, conducted by the researcher, Lauren Kadwell. Individual interviews can be conducted via the telephone if convenient, or face-to-face at a suitable location. During this interview, I will be interested in your personal experiences of discussing sexuality and intimacy with patients and/or their partners. This discussion will be audio-taped to allow me to go over what is said
in detail afterwards. This discussion will be strictly confidential. It will take you no longer than one hour.

What are the benefits? This study will provide you with an opportunity to discuss your experiences of discussing intimacy and sexuality with your patients and their partners, and will assist in identifying what further training and resources you would require in order to feel better equipped in attending to the sexual and intimate needs of your patients.

Who is running the study: Lauren Kadwell is running this study as part of a Doctor of Philosophy (Psychology) thesis, under the supervision of Dr Emilee Gilbert and Professor Jane Ussher from the Centre for Health Research, School of Medicine at the University of Western Sydney, and Professor Liz Lobb from the School of Medicine at the University of Notre Dame. This study has been approved by the University of Western Sydney Research Committee (HREC 9397).

I want to participate. What do I do?
Contact Lauren Kadwell at l.kadwell@uws.edu.au. You can also request more information about the study.
Appendix 3: Participant Information Sheet and Consent Form

Human Research Ethics Committee
Office of Research Services

Participant Information Sheet (General)

Project Title: Talking about sexuality and intimacy: Health professionals in a palliative oncology context

Who is carrying out the study?

Lauren Kadwell under the supervision Dr Emilee Gilbert, Professor Jane Ussher, and Professor Liz Lobb.

You are invited to participate in the above titled research being undertaken by Lauren Kadwell, as part of a Doctor of Philosophy (Psychology) thesis, under the supervision of Dr. Emilee Gilbert (Centre for Health Research, School of Medicine, University of Western Sydney), Professor Jane Ussher (Centre for Health Research, School of Medicine, University of Western Sydney), and Professor Liz Lobb (Adjunct Professor, School of Medicine, University of Notre Dame).

What is the study about?

The purpose of this study is to investigate how health care professionals (doctors, nurses, social workers, psychologists and counsellors) communicate with patients and/or their partners about sexuality and intimacy in a palliative oncology context. The aim of this research is to explore: How health professionals view sexuality and intimacy in the context of palliative care; their experiences of discussing (or not discussing) sexuality and intimacy with patients and/or their partners; and to identify what training or resources that health professionals may have accessed that have assisted them to attend to the sexual and intimate needs of people with cancer and/or their partners. This study will also identify areas of unmet need for health professionals in relation to the provision of information and communication about sexuality and intimacy.

What does the study involve?
You can choose to participate in either a one-off, individual interview, or in a focus group, with the researcher, Lauren Kadwell. Participation in this study will take approximately 45 minutes to one hour. Individual interviews can be conducted via the telephone if convenient, or face-to-face at a suitable location. During the interview/focus group, I will be interested in your personal experiences of discussing sexuality and intimacy with patients and/or their partners, and whether you have experienced training or accessed resources which have assisted you to attend to the sexual and intimate needs of patients and/or their partners. This discussion will be audio-taped to allow me to go over what is said in detail afterwards. This discussion will be strictly confidential. Please sign the attached consent form if you are happy to participate.

**How much time will the study take?**

The interview should take no longer then one hour.

**Will the study benefit me?**

This study will provide you with an opportunity to discuss your experiences of discussing intimacy and sexuality with patients and their partners, and will assist in identifying what further training and resources you would require in order to feel better equipped in attending to the sexual and intimate needs of patients and their partners.

**Will the study involve any discomfort for me?**

Sexuality and intimacy, particularly in the context of palliative care, are often difficult topics to talk about, and has the potential to raise personal concerns. During the course of the interview you may find that talking about these topics will trigger negative emotions for you. The researcher is 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 Lauren Kadwell on (02) 4620 3958. Alternatively, if you do not want to speak to the researcher, you can contact the NSW Cancer Council Helpline on 13 11 20, who can provide independent advice and counselling.

**How is this study being paid for?**

This study is not sponsored. It is being conducted as part of a Doctor of Philosophy (Psychology) thesis.

**Will anyone else know the results? How will the results be disseminated?**

All aspects of the study, including results, will be kept confidential and only the researchers will have access to your details. The results will be held securely at the University of Western Sydney. The results will be disseminated in the form of a Doctor of Philosophy thesis, which may lead to publication in a refereed academic journal article, and in this thesis all information will be summarised and no one will be mentioned by name.
Please keep in mind, when considering whether you wish to participate in a focus group, that during the focus group you may recognise, or be recognised, by other health professionals (for example, other health professionals in the focus group may come from your workplace). If this is of a concern to you, you may wish to consider taking part in an individual interview instead.

**Can I withdraw from the study?**

Please note that your participation in this study is entirely voluntary. You are not obliged to be involved and you can withdraw from the study at any time without giving any reason and without consequences. If you do choose to participate you will be asked to complete the provided consent form.

**Can I tell other people about the study?**

Yes, you can tell other people about the study by providing them with the chief investigator's contact details. They can contact the chief investigator to discuss their participation in the research project and obtain an information sheet.

**What if I require further information?**

When you have read this information, Lauren Kadwell will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Lauren Kadwell at l.kadwell@uws.edu.au.

**What if I have a complaint?**

This study has been approved by the University of Western Sydney Human Research Ethics Committee. The Approval number is H9397.

If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229 Fax +61 2 4736 0013 or email humanethics@uws.edu.au.

Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

If you agree to participate in this study, you may be asked to sign the Participant Consent Form.
Participant Consent Form

Project Title: Talking about sexuality and intimacy: Health professionals in a palliative oncology context

I, .................................., consent to participate in the research project titled - ‘Talking about sexuality and intimacy: Health professionals in a palliative oncology context’. This research is being undertaken by Lauren Kadwell, as part of a Doctor of Philosophy (Psychology) thesis, under the supervision of Dr. Emilee Gilbert, (Centre for Health Research, School of Medicine, University of Western Sydney), Professor Jane Ussher, (Centre for Health Research, School of Medicine, University of Western Sydney), and Professor Liz Lobb (Adjunct Professor, School of Medicine, University of Notre Dame).

I acknowledge that:

I have read the participant information sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I consent to taking part in either an individual interview or focus group with Lauren Kadwell and to having the interview audio-taped.

I understand that my involvement is confidential and that the information gained during the study may be published but no information about me will be used in any way that reveals my identity.

I do not expect to obtain any direct personal benefit from this study.

I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future.

What if I have a complaint? This study has been approved by the University of
Western Sydney Human Research Ethics Committee. The Approval number is H9397. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Office of Research Services on Tel +61 2 4736 0229, Fax +61 2 4736 0013 or email humanethics@uws.edu.au. Any issues you raise will be treated in confidence and investigated fully and you will be informed of the outcome.

Signed:  

Name:  

Date:
Appendix 4: Interview Schedule: Health Care Professionals

Demographics to collect before interview:

- Age
- Cultural background
- Hospital or community-based
- Length of time in palliative care field
- Previous work experience related to palliative care field (e.g. aged care, oncology)
- Description of the area that they work in - (i.e. metropolitan, regional, rural or remote).

Semi-structured interview question areas:

1. Could you begin by telling me how you see intimacy and sexuality in the context of cancer and palliative care?

   Prompt - How would you define sexuality and intimacy?

2. Can you tell me about your experiences of discussing sexuality and intimacy with people with cancer who are receiving palliative care?

   a) With their partner?

   - If response is "not much [experience]" - Can you tell me about a time when you talked about sexuality and intimacy? prompts - How did you feel during this discussion/having this discussion.

3. Have there been times when patients or their partners have raised issues around sexuality and intimacy with you?

4. What are some of the barriers you think patients, or couples, face with
intimacy and sexuality in the context of cancer and palliative care?

5. How do you feel about talking about changes to sexuality and intimacy post-cancer? Difficulties, things that worked, things that are considered important

6. How do you start the conversation? What works? When is it easier to raise? Do you talk to the patient? The partner? Or both?

7. Do you have any strategies that assist you to respond to, or facilitate, the sexual and intimate needs of your patients?

8. What, if anything, has assisted you to respond to the sexual and intimate needs of your patients, or couples?

9. Has anything prevented you, or made it more difficult for you to respond to the sexual and intimate needs of your patients?
   a) If yes, how? And if possible, how could it be changed?

10. Do you think the culture or environment at your work currently supports your attempts to facilitate sexuality and intimacy for patients/between couples?
   a) If yes, how?
b) If no, how could it be changed?

11. Whose role do you think it is to address sexuality and intimacy with patients and their partners?

   a) What aspects of sexuality and intimacy should they address?

12. Tell me about the type of training or resources you have received in the area of sexuality and intimacy

   a) Adequate?
   b) From whom?

13. What other training or resources would you like access to?

**Closing statement**

14. Is there anything else about your experience as a health professional that you would like to talk about?