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**Couples Living in Twilight:
A Heideggerian Hermeneutic Study of
Sexuality and Intimacy in Life-limiting Illness**

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Doctor of Philosophy

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Abstract

The purpose of this study has been to understand the experiences of people living with a life-limiting illness in relation to sexuality and intimacy. Although the healthcare literature advocates that sexuality is addressed as part of holistic care, there is insufficient research evidence to guide healthcare professionals caring for people with life-limiting illnesses. It is unclear whether the current empirical evidence relating to the experiences and sexuality concerns of patients who are diagnosed with a life-threatening illness can be extrapolated to those nearing the end of life. Although the End of Life Strategy (Department of Health 2008) advocated identifying individuals' wishes and preferences regarding their care, it is still unclear whether it is appropriate for healthcare professionals to broach the topic of intimacy and sexuality with terminally ill patients and their partners.

In this Heideggerian hermeneutic phenomenological study, I have explored the meaning of sexuality and intimacy for patients and partners of patients who have life-limiting illnesses. I held conversational interviews with 27 patients and 14 partners of patients who had either terminal cancer or motor neurone disease. Consistent with Heidegger's (1962) hermeneutic circle of interpretation, I used an adaptation of Diekelmann's (1992) iterative approach to analyse the data.

This study brings new understanding of the human condition. When someone is diagnosed with a life-limiting illness, it is not only their life that is limited, but the life of the couple is also dying. In their 'being-towards-death-of-the-couple', the participant who was dying and their partner experienced 'connecting', 'disconnecting' and, sometimes, 're-connecting'. The meaning that intimacy and sexual expression held for individuals was threatened by a range of factors including bodily changes, the physical barriers imposed by 'enabling' equipment, and death itself. Some participants were able to find alternative ways of connecting with their partner, while others mourned the loss of their coupled relationship and the potential for repair.

These aspects of people's lives were rarely broached by healthcare professionals. Although participants were unclear what role healthcare professionals might have, many reflected upon the value of being able to talk about their experiences. In concluding this thesis, I have provided suggestions for education, research and healthcare practice.

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Introduction

Here is a place of disaffection
Time before and time after
In a dim light: neither daylight

(Eliot 2001a:6)

Twilight is a period that is betwixt and between, it is neither light nor dark, neither day nor night. For couples living with a life-limiting (terminal) illness, the future is both certain and uncertain; in their living towards death, they are between life and death. The twilight of their years has been brought into nearness for them when one partner is diagnosed with a life-limiting illness. In coupled relationships, life-limiting illness affects both the person who is diagnosed and their partner.

Personal accounts have shown that when people receive a life-threatening diagnosis, it prompts them to 'take stock' and re-evaluate what is meaningful in their lives (Arthur and Arthur 2000; Brock 2004; Diamond 1998; Ellis 1995; Frank 2002). Life-threatening illness impacts upon an individual's sense of wholeness, independence, control and certainty, as well as their social world (Toombs 2008). This extends far beyond the experience of one's physical body, as people are faced with the question:

What does this illness mean for me in my relationship with others?

(Toombs 2008:4)

This thesis considers the place that sexuality and intimacy have in the lives of individuals whose condition does not respond to curative treatment: people living with a life-limiting illness. The life-limiting illnesses included in this study are advanced cancer and motor neurone disease (MND¹).

¹ MND, also known as ALS (amyotrophic lateral sclerosis) or Lou Gehrig's disease, is a progressive neurodegenerative disease that initially weakens and eventually destroys motor neurones. As the motor neurones deteriorate, so too does the individual's ability to control the muscles of movement, speech, swallowing and breathing. It is both incurable and fatal. Life expectancy from the first symptoms is, on average, three to four years (Talbot et al 2010).

The impetus for this study

I have undertaken this study because the phenomenon matters to me (Drew 1989). In my experience as a palliative care nurse in a hospice, there has been very little recognition of patients' sexuality. Colleagues have often told me that sexuality is not relevant when people are dying. Several have said: "people have far more important things to worry about than sexuality". However, when I have raised the subject with patients, some have been glad of the opportunity to discuss their concerns.

Dame Cicely Saunders, the founder of the modern hospice movement, has said:

You matter because you are you. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but also to live until you die.

(Saunders 1976:1005)

These words have been pivotal in establishing the ethos of organisations around the world that are concerned with caring for people nearing the end of their life, and are still cited today (African Palliative Care Association 2012; American Cancer Society 2011; National Gold Standards Framework Centre 2012; St Luke's Hospice 2010; The Rowan's Hospice, no date). I am called to ask, however, what it means to live until one dies. Is sexuality a part of life for people who are dying? Is it an aspect of care that healthcare professionals should address?

A central feature of the End of Life Strategy (Department of Health 2008) involves identifying and responding to individuals' wishes and preferences. The primary goal of palliative care (upon which hospices are founded) is to improve quality of life (Richards and Ramirez 1997). Although quality of life is a difficult concept to define, there is clear guidance that this requires a whole-person (holistic), multi-dimensional approach which encompasses both the individual with the life-limiting illness and those that matter to them (National Council of Hospice and Specialist Palliative Care Services 1993). Family members are considered to be "co-clients" (Addington-Hall 2002:222), so it is important that research into people's experiences does not exclusively focus upon patients

(Addington-Hall 2002). In the context of sexuality, I therefore believe it is essential to consider the perspective of partners² too.

Explanation of terms

Defining holism

Holism is a core value of healthcare practice that is explicitly endorsed by professional bodies that include nursing (Nursing and Midwifery Council 2010), medicine (Allen et al 2007) and physiotherapy (Chartered Society of Physiotherapy, no date). The philosophy of holism reflects the World Health Organisation's (2001) bio-psycho-social approach to health, and requires professionals to consider more than the physical effect of disease, but to recognise each individual's unique experience within their social and cultural context (Dossey et al 2008).

The ethos of holistic care therefore requires healthcare professionals to assess all aspects of an individual's health, including the cultural, physical and psycho-social elements, with the intention of identifying need and delivering care to meet that need. If healthcare professionals are to use a holistic framework as the basis of caring, issues of sexuality will, by necessity, need to be incorporated into the assessment, planning, delivery and evaluation of care.

It has long been recognised that sexuality falls within the remit of holistic care (Glover 1985; Haboubi and Lincoln 2003; Higgins et al 2006; Magnan et al 2005; Mick 2007; Odey 2009; Oliviere et al 1998; Redelman 2008; Royal College of Nursing 2000; Saunamäki et al 2010; van Ooijen and Charnock 1994). The Royal College of Nursing (2000:2) have described sexuality as "a legitimate area of nursing activity". More recently, this has been endorsed by the Nursing and Midwifery Council (2009) in their publication, *Guidance for the Care of Older People*. This document explicitly requires nurses to identify and meet people's sexual and relationship needs, regardless of their age:

The importance of the influence of an older person's life history and personal circumstances should not be underestimated. Therefore personal and family

² By partners, I include people who are married, in a civil partnership, co-habiting and those in coupled relationships who live apart.

relationships, social networks, previous occupation, sexual, cultural and spiritual needs should all be discussed as an integral part of ongoing assessment.

(Nursing and Midwifery Council 2009:21)

This important guidance specifically establishes sexuality as a legitimate aspect of the lives of older people, and endorses nurses' role in including this aspect of people's lives within holistic care.

Defining sexuality

The academic healthcare literature consistently conceptualises sexuality in broad terms, of which sexual behaviour is not the only element (Bauer et al 2007; Gamlin 2005; Monroe and Sheldon 2004; Northcott and Chard 2000; Odey 2009; Peate 2010; Rice 2000; Shell 2008). Sexuality has been described as multi-faceted, involving more than just the biological and physiological components of sexual behaviour and reproduction (Béphage 2008; Hodge 1995); it encompasses psychological and sociological aspects of how an individual relates to themselves and the world at large (Hodge 1995).

Sexuality is therefore expressed in how we dress, how we feel about ourselves, our relationships, and how we communicate with those around us (Medlar and Medlar 1990; Newson 2007). In addition to sexual activity, sexuality encompasses self-concept and body image; "the way we perceive our appearance and attractiveness to self and others" (Gamlin 2005:200). Shope (1975:3) extended this further and suggested that sexuality involves:

The total characteristics of an individual - social, personal and emotional - that are manifest in his or her relationships with others.

It would seem, therefore, that sexuality is something that we express, in relationships with others as well as with ourselves. Sexuality is not a preserve of the young (Newson 2007), though it does change "in response to maturational, physiological, social and psychological events" (Davis and Taylor 2006:103). Illness and disease will influence individuals' sexuality (Hughes 2000).

The research literature, however, is not consistent with this view. Hordern's (2008) comprehensive literature review of cancer and palliative care literature spanning over 30 years has shown an over-emphasis on sexual function:

There seems to be an overall belief that the term 'sexuality' is inextricably linked with sexual intercourse.

(Hordern 2008:11)

In order to overcome this physiological and behavioural bias, it is perhaps more useful to emphasise that, although sexuality can involve sexual behaviour, when expressed in a relationship, it also involves "companionship, love [and] intimacy" (Aitken 2009:72).

Defining intimacy

There is a lack of clarity in the literature regarding what is meant by 'intimacy' (Hordern 2008), with many authors (Burbie and Polinsky 1992; Hordern 2000) using the term but neglecting to define it. Like sexuality, intimacy is often used as a euphemism for sexual behaviour (Butler et al 1998). Of the few who have defined it, de Vocht (2011:15) recognised that "physical intimacy cannot be regarded in isolation from emotional intimacy", yet restricted her study to affectionate touch and sexual release.

Other authors have recognised that intimacy is not reliant upon physical contact, but is a means of communication (Gamlin 2005; Little et al 2001). An intimate relationship is not necessarily a sexual one (Leviton 1978), but involves trust and an emotional attachment or closeness (Jamieson 2005; Peate 2010). Intimacy involves sharing and confiding (Leviton 1978), and is also a means of communicating love "through words, looks and gestures" (Gamlin 2005:200).

The purpose of this study

In order to inform my own and others' healthcare practice, this study sets out to:

- ◆ Understand how patients and partners of patients³ who have life-limiting illnesses experience sexuality and intimacy.
- ◆ Understand shared meanings of sexuality and intimacy for patients and partners of patients who have life-limiting illnesses.
- ◆ Learn from the experiences of patients and partners of patients living with life-limiting illness in order to inform healthcare practice.

³ I acknowledge that there is more to each individual than whether or not they have the life-limiting condition in question. I have merely used the terms 'patients' and 'partners' for brevity and clarity.

Research questions

In order to meet the above-stated aims, my research questions are:

- ◆ What are the experiences of patients and partners of patients who have life-limiting illnesses in relation to sexuality and intimacy?
- ◆ How do people living with a life-limiting illness make sense of their experiences of sexuality and intimacy?

The structure of this thesis

Chapter 1 Narratives in the world

There are a variety of prevailing discourses around sexuality that have appeared in historical, religious, anthropological, sociological, psychological and healthcare literature. Some of these pervade popular culture. This chapter uses seminal work to present an overview of the dominant discourses, and discusses what is already known about sexuality and intimacy for people living with life-limiting illness.

Chapter 2 Philosophical perspectives

The questions I have asked and the interpretations I have revealed are informed by the philosophical lens of Heideggerian hermeneutics. This chapter discusses Heidegger's philosophy of hermeneutic phenomenology, and explains the relevance of several of his concepts for understanding people's experiences of being-in-the-world. These concepts include 'temporality', 'being-towards-death', 'ready-to-hand', and the hermeneutic circle of understanding.

Chapter 3 Method

This chapter presents the 'thinking' and 'doing' of this study. It discusses my decision-making process and the steps involved when I recruited participants, gathered and interpreted their stories. The ethical considerations are described, my rationale for adapting Diekelmann's (1992) iterative process for analysis is presented, and de Witt and Ploeg's (2006) framework for establishing rigour is discussed. Finally, the emerging themes and constitutive pattern are presented in diagrammatic form to illustrate conceptually how the 'whole' and the 'parts' co-exist.

Chapter 4 Contextualising my interpretations

This chapter discusses the context within which the new understandings have arisen. My background, values and beliefs have inevitably influenced the topic for this study, as well as my choice of design, data collection and data analysis. This chapter discusses not only my position as gatherer and interpreter of people's stories, but also explains how participants' experiences of sexuality and intimacy are understood within their own fore-structures of understanding. The new understandings that have emerged from this study are therefore set within these contexts, and establish sexuality and intimacy as embodied, relational experiences.

Chapter 5 Sexuality and intimacy as connecting

This chapter presents the first of the themes arising from this research: 'sexuality and intimacy as connecting'. Connecting is a quality of relatedness, of being-with. Participants described masturbation as a poor substitute for connecting with their partner, and experienced connecting through sex as bonding, sex-as-a-gift-for-the-other, and sex as mutual exchange. As an embodied experience, connecting was not always reliant upon sex, as it was also experienced through non-sexual touch. For these patients and partners of patients with a life-limiting illness, connecting was experienced while living in the shadow of impending death.

Chapter 6 Sexuality and intimacy as disconnecting

Informed by the previous chapter, this chapter discusses sexuality and intimacy when participants experienced them as 'disconnecting': becoming apart as a couple. For some participants, previous sexual difficulties or previous sexual violence impeded connecting with their partner; in these narratives, disconnecting was experienced as a legacy from the past.

Disconnecting was experienced in a variety of ways: as loss of spontaneity, as lack of reciprocity, as rejection, and as 'rights and duties'. It was influenced by technology and was experienced through disfigurement, lack of privacy and through experiences of 'becoming'. Some participants described disconnecting from their partner through becoming a different person, through becoming a 'patient', or through becoming a 'carer'. Disconnecting was experienced 'in the shadow of impending death' and, unspoken, sexuality and intimacy were 'silent bedfellows'.

Chapter 7 Being-towards-death as re-connecting

Some participants described experiences of sexuality and intimacy as 're-connecting' with their partner, becoming closer as a couple. Participants experienced this during moments when they became acutely aware of the prospect of death as a reality; when 'in the shadow of impending death'. This chapter presents the finding that one partner's being-towards-death provided possibilities for re-connecting as a couple.

Chapter 8 Being-towards-death-of-the-couple

This chapter describes the theme 'an illness shared', where both the patient and their partner (vicariously) were diagnosed with and living with life-limiting illness. Within this context, the theme of 'time running out' is discussed, where participants recognised the 'being-towards-death' of their coupled relationship. Theories of loss and grief are applied in order to further understand participants' experiences.

Chapter 9 What place do sexuality and intimacy have in healthcare practice?

This chapter considers the place of sexuality and intimacy within holistic healthcare. It discusses the silence that participants experienced around sexuality and intimacy, and considers this within the concept of disenfranchised loss. It presents participants' suggestions for healthcare practice, and considers reasons why this aspect of care is not addressed by healthcare professionals.

Chapter 10 Challenges experienced and lessons learned

This chapter reflects on the processes involved in gathering and understanding people's experiences of sexuality and intimacy. It discusses the recruitment challenges, and the strategies I used to overcome them, and considers issues of harm and maintaining safety for the research team. It demonstrates the value of maintaining a reflective journal when discussing my reactions and responses to several challenging situations, and further illustrates my position in co-constructing the data and the emerging understandings. The discussion is concluded by outlining some of this study's limitations.

Chapter 11 Conclusions

In drawing this thesis to a close, this chapter proposes suggestions for clinical practice, education and research.

Chapter 1: Narratives in the world

Introduction

There are multiplicities of discourses on sexuality (Caplan 1987; Weeks 1986). These are evident in religious, historical, anthropological, sociological and psychological literature, as well as in popular culture. This chapter is divided into two parts. The first section presents a historical overview of some of the seminal work in this area and illustrates how these narratives are played out in popular culture. This overview illustrates how different narratives mesh with each other, and provides a context in which this study is situated. In the second section, the findings from a review of the healthcare literature are discussed to establish what is currently known about sexuality and intimacy in life-limiting illness.

Part 1 ~ An overview of sex and sexuality within a historical context

Despite the healthcare literature purporting to view sexuality holistically (Béphage 2008; Gamlin 2005; Hodge 1995; Newson 2007), several dominant discourses have tended to equate sexuality with sexual intercourse (Ellis 1913; Ford and Beach 1952; Freud 1933; Freud 1925; Kinsey et al 1953; Kinsey et al 1948; Masters and Johnson 1966). This section therefore discusses the portrayal of sexuality as purposeful behaviour before considering some of the discourses of control and power.

Sex as purposeful behaviour

Sexual activity has been portrayed in the literature as purposeful behaviour in the context of reproduction, pleasure, love and performance.

Sex as reproductive activity

Plato is often misconstrued as having argued against homosexuality, but Veyne (1985:27) argued:

His plan is not to passion back to strictly natural habits by only allowing love for women, but to suppress it altogether, only allowing sexual activity for the purpose of reproduction.

At the end of the 16th century, the theologian Thomas Sanchez wrote that to gain pleasure from the sexual act was not in itself a sin, but pleasure should not be the intention (Flandrin 1985); procreation was considered the sole purpose of sex. Theologians believed that female orgasm (considered to be the emission of female 'semen') and simultaneous orgasm increased the likelihood of conception and were therefore permissible (Flandrin 1985). 'Unnatural positions', however, were considered to be in pursuit of pleasure (rather than reproduction), and were therefore not accepted (Flandrin 1985).

The value of sex as 'natural' and procreative continued throughout 18th and 19th century Britain, and any form of non-procreative sex was deemed unnatural (Feldman 1984). This discourse on sexuality, which views sex as reproductive activity, has strongly influenced the primacy of heterosexuality (Jackson 1984a).

Christian doctrine supports sex within marriage for the purpose of procreation, but also considers sex a marital duty. The marital obligation to have sex is written into the modern marriage vows, as both the husband and wife pledge, "with my body I honour you" (Church of England 2000).

Sex as pleasurable activity

Even though in the 1800s sex was not considered pleasurable for women, there was an expectation that men would still 'take their pleasure' and therefore this was something that women had to learn to endure. Smythers (2008:21-26) wrote in 1894:

While sex is at best revolting and at worse rather painful, it has to be endured, and has been by women since the beginning of time, and is compensated for by the monogamous home and by the children produced through it. It is useless, in most cases, for the bride to prevail upon the groom to forego the sexual initiation. While the ideal husband would be one who would approach his bride only at her request and only for the purpose of begetting offspring, such nobility and unselfishness cannot be expected from the average man. Most men, if not denied, would demand sex almost every day.

Men are portrayed here as somewhat unfeeling animals with an innate sexual drive that needed to be curbed. The unsavoury notion of female (and male) sexuality is evident in Smythers' (2008:18) dictum, "Give little, give seldom, give grudgingly".

Freud (1933; 1925) considered sexuality as the basis of all experience. He recognised that the clitoris was considerably more sensitive than the vagina in young women, but argued that psychosexual maturity involved the subordination of clitoral sensation and its replacement with vaginal sensitivity. His discourse on clitoral stimulation as 'immature' rendered it unacceptable as part of the sexual act, so the focus of the marriage manuals in the 19th century was purely centred on vaginal intercourse (Ehrenreich and English 1979). Women were expected to "renounce the pleasures of the clitoris and attempt to transfer all sexual feeling to the vagina" (Ehrenreich and English 1979:271). This rejection of the clitoris symbolised a woman's abandonment of 'penis envy' (Freud 1933; Freud 1925) and acceptance of her life as a passive sexual partner.

Masturbation in women ('the vice') was considered a form of self-abuse and was attributed to be a cause of menstrual problems, genital lesions, tuberculosis and even dementia (Ehrenreich and English 1979). Women's sexuality was not only suppressed, but also considered a threat to men:

The over-sexed woman was seen as a sperm-draining vampire who would leave men weak, spent and effeminate.

(Ehrenreich and English 1979:127)

Early recognition of sex being pleasurable and transformative for women caused considerable public outcry. In DH Lawrence's (1960) *Lady Chatterley's Lover*, Lady Chatterley's husband, Sir Clifford, was paralysed on the battlefield and confined to a wheelchair within months of their marriage. Becoming dissatisfied with her marriage, Lady Chatterley (Connie) embarked upon a sexual relationship with her husband's gamekeeper and became pregnant. The scandal that this book generated was not because of the relationship crossing class barriers, for this had been the theme in previous novels of its time (Becket 2002), but because of its explicit sexual content. Lawrence himself was aware of the potential for this, as he wrote in a letter to a friend:

I've done my novel – I like it – but it's so improper, according to the poor conventional fools, that it'll never be printed.

(Gant 1972:v)

Lawrence self-published his work in Florence in 1928 (Lawrence 1972) and the book was banned in America and England. When the modified version was published in England in

1960, Penguin Books was prosecuted (unsuccessfully) under the 1959 *Obscene Publications Act* (Young 1960).

The acceptability of sex as a pleasurable activity for women came to be recognised by the Dutch gynaecologist, van de Velde. In his book, *The Ideal Marriage*, he advocated “equal rights and equal joys in sexual union” (van de Velde 1930:145), advocating that both partners should experience sexual pleasure (van de Velde 1930). This heralded a complete turnaround in public discourses on sex and, as Brecher (1970:82) stated, van de Velde “taught a generation how to copulate”. The book presented a variety of means of sexual expression between couples, and stated that oral sex was both permissible and enjoyable (van de Velde 1930). However, van de Velde’s (1930:145) detailed and explicit guidance made clear distinction between foreplay (“love-play”) and the purpose of sexual activity - “sexual union”. It recognised clitoral stimulation as pleasurable, but only as a prelude to ‘proper’ sex in the form of vaginal intercourse. Van de Velde (1930) also expected simultaneous orgasm to arise from vaginal stimulation (for both partners).

It was not until the 1950s that Kinsey et al’s (1953) research “debunked the myth of the vaginal orgasm” (Scully and Bart 1973:1047). Critical of previous studies that had relied upon questionnaires to collect data, Alfred Kinsey (1894-1956) and his colleagues at Indiana University conducted ground-breaking research by interviewing 6,300 men and 5,300 women from all of the American states about the frequency of their sexual behaviours. Their publications in 1948 (Kinsey et al 1948) and 1953 (Kinsey et al 1953) remain the largest and most detailed studies of human sexual behaviour. Their findings were controversial as they not only brought into the public arena matters that were previously unspoken in the public domain, but they also challenged conventional beliefs about women’s sexuality and homosexuality.

Kinsey et al’s (1953; 1948) findings challenged the binary view of sexual behaviour and sexual attraction (to either the same or opposite sex) as ‘fixed’, because they found that, for many people, they were subject to change over time. They also found that women were more sexual than had otherwise been accepted. Their research revealed that, for many women, the vagina was not the main orgasmic sensory centre. In most women, they found the clitoris to be the main erogenous zone and that many women were capable of multiple orgasms. Despite this, a review of gynaecology textbooks published after this time has shown that many of them continued to portray men as having a stronger sexual drive,

describing women's sexual drive as being focussed on reproduction, not pleasure (Scully and Bart 1973).

In 1959, William Masters and Virginia Johnson pioneered research into the anatomy and physiology of the human sexual response. They observed and measured sexual intercourse and masturbation in heterosexual and homosexual dyads by randomly assigning couples in what they estimated to be "10,000 complete cycles of sexual response" (Masters and Johnson 1966:15). One of their significant findings resulted in the categorisation of the 'human sexual response cycle' (Masters and Johnson 1966). Although largely a physiological study, Masters and Johnson (1966) framed their findings in language that presented sex as a healthy activity that could be enjoyed as a source of pleasure, and dispelled many long-standing misconceptions, particularly in relation to female sexual arousal and orgasm. They found that there was no absolute age at which arousal and sexual function ceased and refuted the misconception that women are inherently less sexual than men (Masters and Johnson 1970). More recent research confirms that sexual activity remains important to older people (Gott and Hinchliff 2003).

The discourses on sex as a pleasurable activity have changed notably since then, particularly in relation to women. The advent of the contraceptive pill removed sex from reproduction and motherhood, and an increasing emphasis on sexual pleasure became possible (Giddens 1992). Where women's sexual pleasure was previously unrecognised (and even disapproved of) in public discourses, women have come to view a fulfilling sex life as essential for a happy marriage (Rubin 1990). Voicing one's wishes and negotiating with one's partner is now recognised as an important means of ensuring mutual pleasure (Marsden and Taylor 2012a; Marsden and Taylor 2012b; Martyn 2003; Quilliam 1995).

However, patriarchal attitudes do still persist in discourses on sexual pleasure. The recently updated sex manual, *Joy of Sex* (Comfort and Quilliam 2008), despite its detailed discussion of a variety of sexual practices and positions, continues to focus upon vaginal intercourse as the ultimate experience. Presenting 'gourmet lovemaking', the authors describe heterosexual sex as a menu, with 'appetizers' as a prelude to the 'main course'. This suggests that discourses on heterosexual sex, while promoting pleasure, continue to

favour intercourse as the ultimate experience, despite vaginal stimulation having been shown to have limited orgasmic effect for many women (Hite 1976; Kinsey et al 1953)⁴.

Sex as an expression of love

Kinsey et al (1953) have been criticised for their emphasis on “sex as sex”, and neglecting to recognise love as an integral component of sexual behaviour (Galdston 1954).

However, in addition to the interview research described above, Kinsey et al (1953) conducted an innovative study by surveying male and female toilets in order to compare the graffiti created by men and women. In the 259 male toilets, 86% of the inscriptions were explicitly sexual, compared to only 25% of the inscriptions produced by women (n=94). The majority of the female inscriptions referred to relationships, referring to ‘love’ or pairing two names together. While suggesting that women might be less inclined to write on toilet walls because of their adherence to moral codes, other data showed that women were less likely to be aroused by erotic images or fantasies than men (Kinsey et al 1953). This is supported by the sociologists, Gagnon and Simon (2005), who found that women were sexually aroused by films where relationships were portrayed, but not by sexual images. Their study concluded:

For most women, including most lesbians, the pursuit of sexual gratification as something separate from emotional or romantic involvement is not particularly attractive.

(Gagnon and Simon 2005:136)

It is evident from these two teams of researchers that women do not respond to sexual images “at an emotional distance” (Gagnon and Simon 2005:137). For women, sex would therefore appear to be situated within the context of a relationship.

Further evidence of this narrative of difference between men and women appeared in the Meatloaf Song *Paradise by the Dashboard Light* (Steinman 1977). The song began with a couple reminiscing about a night when they were “barely 17” and sitting in a car beside a lake. The boy believed “we’re gonna go all the way tonight”, and just as he was about to “steal home base” (have intercourse), the girl burst out:

⁴ Discourses on sex as pleasurable activity for gay men have been absent from mainstream discourses. In *The Joy of Gay Sex*, it is notable that Silverstein and Picano (2004) have presented no such hierarchy of sexual activities; all sexual practices have been given equal place within sexual encounters.

Stop right there!
I gotta know right now!
Before we go any further

Do you love me?
Will you love me forever?
Do you need me?
Will you never leave me?
Will you make me so happy for the rest of my life?
Will you take me away and will you make me your wife?

(Steinman 1977)

The girl refused to go any further unless he promised to love her “to the end of time”. Reluctant to make such a long-term commitment, the boy prevaricated by saying he would “sleep on it” and give her an answer the following day. She persisted and he eventually gave in:

I couldn't take it any longer
Lord I was crazed
And when the feeling came upon me
Like a tidal wave
I started swearing to my god and on my mother's grave
That I would love you to the end of time
I swore that I would love you to the end of time!

(Steinman 1977)

This song conveyed the narratives of over-whelming sexual desire in men (as an end in itself) which, in contrast to women, did not require the commitment to a relationship or a promise of marriage. In the boy’s belief that “you gotta do what you can and let Mother Nature do the rest”, the idea of a natural sexual drive is apparent. The girl was prepared to have sex in exchange for a commitment of love “to the end of time”, and the boy eventually recognised that this promise of exchange was a pre-requisite to sexual intercourse. In the economics of sex, women have required the physical act to be exchanged for an emotional quid pro quo.

Giddens (1992:62) has drawn a distinction between 'passionate love' (*amour passion*), which is purely erotic, and 'romantic love', which is companionable and involves 'a meeting of souls'. Romantic love is not without passion, but is enduring and involves "a feeling of wholeness with the other" (Giddens 1992:61). In contrast to romantic love, which is contingent upon 'a special person', 'confluent love' is contingent upon 'a special relationship' (Giddens 1992:61). Giddens (1992:145) coined the term the 'pure relationship' to describe modern relationships that have evolved from an 18th century view of romantic love and involve "an opening out of oneself to another". These relationships are contingent (for now) and are based upon 'confluent love'. 'Pure relationships' are not exclusively heterosexual, do not require permanency or even monogamy, but are based upon equality and open communication.

Sex as performance

Masters and Johnson's (1970) book, *Human Sexual Inadequacy*, was one of the first manuals to provide explicit practical guidance on how to treat premature ejaculation, impotence, orgasmic dysfunction, vaginismus and dyspareunia. The focus on sex as performance has notably expanded since then and is evident today within popular women's and men's magazines (Cosmopolitan 2011a; Cosmopolitan 2011b; Men's Health 2011a; Men's Health 2011b). Variations in sexual positions and sexual practices (such as oral sex) have become legitimised (Cosmopolitan 2011a; Men's Health 2011a).

Headlines on Cosmopolitan's website include, 'Get more sex', 'How to be a bad girl in the bedroom', and 'Dial 'O' for orgasm' (Cosmopolitan no date 1) illustrate the performative nature of sex. Despite the title of the web page being 'Love and sex', the focus upon 'what to do' and 'how', far exceeds any reference to 'love'. This misnomer reflects the shifting discourse on women's sexuality; from one of love, to one of desire and achieving sexual satisfaction.

For women, there is a strong emphasis on performing in such a way as to please one's partner (presumed to be male), though the focus on achieving sexual pleasure for oneself is evident:

Why You'll Love It: You get to focus on your own climax.

(Cosmopolitan no date 2)

In contrast, the focus in *Men's Health* (20011b; 2011c) is on men's sexual prowess. In the article titled, 'How to give her an über-orgasm', acting upon the advice given will apparently:

Make you a sexual genius worthy of a Nobel Prize.

(Men's Health 2011c:126)

While both these magazines portray sex as a pleasurable activity, their emphasis upon sex as performance (in the context of heterosexual relationships) is pervasive. The distinction that I am making between 'sex as performance' and 'sex as pleasurable activity' is that, in the former, one person 'performs' for the other (in giving sexual pleasure) and their actions are intended to be met by orgasmic 'applause', the greater the performance - the greater the applause.

However, when sexuality is seen as performance, it is accompanied by expectations - of oneself and of one's partner. This can be accompanied by a sense of inadequacy - of oneself or of one's partner. This focus upon sex as performance, and the expectations accompanying it, is evident in Rihanna's song, *Rude Boy*:

Come here rude boy, boy, can you get it up?
Come here rude boy, boy, is you big enough?
Take it, take it
Baby, baby
Take it, take it
Love me, love me.

(Eriksen et al 2009)

The expectation here is that the boy will perform to meet her sexual needs. The brief reference to 'love' is merely a euphemism for sex.

It is not only magazines and songs that portray sex as performance. Much of the research literature on sexuality in relation to cancer has focussed on functional aspects of sexuality, with an emphasis on altered erectile capacity and sexual function as a consequence of cancer (Barni and Mondin 1997; Bergmak et al 1999; Cameron et al 2012; Herbenick et al 2008; Rogers and Kristjanson 2002; Stanford et al 2000). The Relate guide for prospective married couples, *Before You Say 'I do'. How to be Happily Married for Ever!* advocates a varied sexual relationship in order to maintain a happy marriage (Martyn 2003).

Sexuality as deviant behaviour

In western societies, male sexual vitality has been considered inevitable and women's vitality dishonourable (Masters and Johnson 1970). However, Kinsey et al's (1953; 1948) research has shown that, although women were less sexually active than men in all aspects of sexual life, they were more sexual than had otherwise been accepted. This would suggest that both men's and women's sexuality is shaped by societal influence.

Indeed, Ford and Beach (1952) conducted a comparative study of patterns of sexual behaviour across 190 different societies, ranging from urban and industrialised to isolated primitive societies, from the Arctic Circle to southernmost Australia. Their main conclusion is that sexual behaviours fall into one of two groups: those that are "the direct expression of the biological nature of man" and those "which derive directly from social customs and pressures and which vary widely... from society to society" (Crew 1952:vii).

Sexuality as a sin against God

Religion has played an important role in the social control of sexual matters. In addition to adultery, the accepted Roman practice of homosexuality between masters and slaves was challenged by the early Christian church. In his first letter to the Corinthians (chapter 6, verses 9-10), St Paul wrote:

Do not fool yourselves; people who are immoral or who worship idols or are adulterers or homosexual perverts or who steal or are greedy or are drunkards or who slander others or are thieves – none of these will possess God's kingdom.

(The Bible Societies 1976:210)

This doctrine heralded the foundation of the Christian abhorrence of homosexuality and the portrayal of it as a sin. In 18th and 19th century Britain, non-procreative sex, in the form of masturbation or homosexuality, continued to be considered by the church to be sinful and against God (Feldman 1984). This view has persisted in the Catholic Church, as illustrated by Joseph Ratzinger only two years before he was elected Pope:

The Church teaches that respect for homosexual persons cannot lead in any way to approval of homosexual behaviour or to legal recognition of homosexual unions. The common good requires that laws recognize, promote and protect marriage as the basis of the family, the primary unit of society. Legal recognition of homosexual unions or placing them on the same level as marriage would mean not only the

approval of deviant behaviour, with the consequence of making it a model in present-day society, but would also obscure basic values which belong to the common inheritance of humanity.

(Ratzinger 2003)

The description of homosexuality as “deviant behaviour” is explained by his view that conjugality can only be achieved by a husband and wife:

Homosexual unions are also totally lacking in the conjugal dimension, which represents the human and ordered form of sexuality. Sexual relations are human when and insofar as they express and promote the mutual assistance of the sexes in marriage and are open to the transmission of new life.

(Ratzinger 2003)

Ratzinger’s (2003) inference that sexual relations between men are inhuman represents an extreme view that is consistent with the biological imperative, that the purpose of sex is reproductive (British Broadcasting Corporation 2010).

The rhetoric of homosexuality as a sin against God (and thus immoral behaviour) was first supported by English law in 1885, when Section 11 of the *Criminal Law Amendment Act* was passed. This act established the offence of ‘gross indecency’, which prohibited homosexual practices (Stonewall, no date). Homosexuality became classified by the medical profession as a ‘mental disorder’ in 1952, and it was not until 1988 that it ceased to be classified as a mental illness (Rose 1994b).

Homosexuality eventually became legalised in the UK (United Kingdom) between consenting men over the age of 21 in 1967 (Feldman 1984). However, it was only in 2001 that the age of consent was equalised for all relationships, and in 2004 that the *Sexual Offences Act* abolished the crime of buggery (Stonewall, no date). Notions of homosexuality as a sin against God are being challenged by the current move by the British government towards legally instituting gay marriage (British Broadcasting Corporation 2012).

Sexuality as a force to be reckoned with

The philosopher and historian, Michel Foucault (1926-1984), challenged the popular belief that the attitude of modern society from the 1700s, through the Victorian era, and

continuing to exert its influence into the 1990s, was one of censorship (Foucault 1998). He argued that the 'repressive hypothesis' was a superficial view that failed to recognise the influence of power in the creation of discourses. Foucault (1998) illustrated this by discussing the significant increase in discourses on sexuality.

In the 17th century, church legislation required penitents to 'examine their consciences' in order to gain self-knowledge about their sexual misdemeanours. Foucault (1998) argued that this did not amount to *self-discovery* of individuals' sexual natures, for "what I am sexually depends on the categories I am required to use in making my confession" (Gutting 2005:93). These categories of deviance were created by the church. Parents were expected to carefully observe their children for symptoms and adults were expected to 'confess' their sins (Ehrenreich and English 1979).

Ironically, the suppression of sexuality by the church meant that it was increasingly spoken about by the very organisation that attempted to control it. Sexuality came to be discussed as something to be managed and controlled. Foucault (1998:17) called this the "veritable discursive explosion".

This religious drive to develop self-knowledge (and to exercise control) through confession has become incorporated within secular society, doctors replacing priests as people with whom we discuss our sexual inadequacies (Abraham 1930). Foucault (1979) argued that the criminal justice system created categories of social dysfunction (such as mass murderer and juvenile delinquent), that are "simultaneously sources of knowledge and control" (Gutting 2005:94), and similarly argued that the science of sexuality created categories of sexual dysfunction that further demonstrated power and control. The legal and medical institutions have defined normality and sought to control and eliminate the abnormal and perverse by their disciplinary power (Foucault 1998).

Foucault's (1998) argument extended beyond the power of medicine and the church. Through industrialisation, it became apparent that the economic stability of a country depended upon its control of the population:

It was essential that the state know what was happening with its citizens' sex, and the use they made of it, but also that each individual be capable of controlling the use he made of it.

(Foucault 1998:26)

Thus “sex became an issue” (Foucault 1998:26) for the state as well as the individual, and the ‘explosion’ of discourses on sexuality extended from the church and medicine to include the political and legal systems (Foucault 1998).

Foucault’s (1998) work has significantly shaped discourses on sexuality in relation to power as sexuality ceased to be seen as a drive in need of repression (Plummer 2005), but as a historically-situated, cultural construct (Caplan 1987). The formulation and control of this construct is achieved by the dominant members of society (usually men) and the institutions they control (Pratt 2000).

Sexuality as a relationship of power

The expression of male power and domination is evident in the work of Havelock Ellis (1913). Ellis (1859-1939) was an influential British psychologist who studied human sexuality. He wrote that women are naturally coy and modest, and advocated that female sexual desire was “an inhibition which has to be conquered” (Ellis 1913, vol.1, p.3). His recommendation was not that women needed to overcome this inhibition, for in doing so they would lose their modesty and would no longer be attractive, but that men played a vital role as conquerors. Ellis (1913, vol.3, p.33) saw force as “the foundation of virility”, and therefore condoned power and force inflicted by men upon women during sex:

To exert power, as psychologists will recognise, is one of our most primary impulses, and it always tends to be manifested in the attitude of a man towards the woman he loves.

(Ellis 1913, vol.3, p.82)

Ellis (1913, vol.3, p.103) argued that he was not “supporting the subjection of women” and legitimised his views by suggesting that the female sexual urge existed as a desire to be conquered; this was expressed as a pretence of resistance (Ellis 1913, vol.6). However, as Ellis (1913) did not distinguish between women’s sexual pleasure and the experience of pain, his support of male power over women would suggest that he did condone the subjectification of women. His portrayal of ‘the art of love’, which required men to arouse in the woman “an emotional condition which leads her to surrender” (Ellis 1913, vol.3, p.69), would, Jackson (1984b) suggested, be more appropriately called “the art of possession and control” (Jackson 1984b:65).

Ellis (1913) was not the only authority to hold these views. Sixty years later, Masters and Johnson (1974) legitimised male power in sexual relationships, arguing that this contributes to women's arousal and pleasure:

The chase is delightful, and it has erotic value for her because being pursued intensifies her sense of herself as a female person.

(Masters and Johnson 1974:70)

Gynaecologists such as Jeffcoate (1967:726, cited in: Scully and Bart 1973:1048) perpetuated these myths and socialised others into the profession through their published textbook:

An important feature of sex desire in the man is the urge to dominate the woman and subjugate her to his will; in the woman acquiescence to the masterful takes a high place.

It is discourses such as these that have justified men's role as the active partner sexually, and cast women into the passive, submissive role.

Kinsey et al (1953; 1948) refuted the notion of male natural aggression and argued against a mind-body dualism that attributed either physiological or psychological reasons for sexual behaviour. They stated that anatomically and psychologically, men might find greater sexual satisfaction through penetration, and "the female may find psychological satisfaction in her function in receiving" (Kinsey et al 1953:592) but this did not account for any differences in aggression between the genders.

Despite their research evidence, relative positions of power persist. Gender-power relations were found to influence women's difficulties in negotiating safer sex 15 years ago (Taylor 1995) and have continued to be of concern (Pulerwitz et al 2002). A survey of 4,762 men and 6,399 women in the UK has shown that women are twice as likely to regret first experience of intercourse, and three times as likely to report being the less willing partner (Wellings et al 2001). This suggests that sexual relations continue to be "a battleground: an area of struggle and power between the sexes" (Jeffreys 1984:24).

Sexuality as identity

Discourses on sexuality have moved from assumptions of fixed, given identities to a recognition of fluidity and the role of 'self' in defining identity (Williams and Bendelow

1998). A recent American survey of 5,865 people aged 14 to 94 years of age found that although 7% of women and 8% of men identified themselves as gay, lesbian or bisexual, a greater proportion of people had participated in same-sex sexual interactions at some point in their lives (National Survey of Sexual Health and Behavior 2010). In the UK survey (n=11,161), 2.6% of men and women reported homosexual partnerships (Johnson et al 2001). These differences between America and the UK are likely to be caused by differences of definition, as well as differing societal values across the intervening years. What these studies have done, however, is show that homosexuality is a normal variant of sexual behaviour.

Sexuality now speaks in many languages, to and for many different types of people, offering a cacophony of alternative values and possibilities.

(Weeks 1986:94)

What were once called 'perversions' are now simply ways of legitimately expressing one's sexuality (Giddens 1992).

As a sociologist, Weeks (1986) considered sexuality within the context of the family, kinship, households and organisation, for it is social interaction that affords actions their meaning and significance. This social interaction was, according to Gagnon (2004) organised around 'sexual scripts'. These scripts are culturally determined rules and norms of behaviour which provide 'lines' and 'roles' for people as though they were actors in a play. In addition to these 'cultural' dimensions, sexual scripts are influenced by 'intrapsychic' and 'interpersonal' dimensions. The intrapsychic dimensions involve the thoughts we have about sexuality and sexual behaviour, and the interpersonal dimensions are those that are played out in dating, courtship, marriage and sexual behaviour. These scripts are often viewed as gender-specific within different cultures.

Giddens (1992) has used the term 'plastic sexuality' to describe sexuality that is freed from reproduction and "the rule of the phallus" (Williams and Bendelow 1998:144), and has become a flexible feature of self. However, the notion of 'plastic' sexuality was not, as might be believed, first coined by Giddens (1992). Berger and Luckmann (1966) used this term when reviewing the work of Malinowski (1927), referring to "the plasticity of the human organism and its susceptibility to socially determined interference" (Berger and Luckmann 1966:67), they argued:

Human sexuality is characterised by a very high degree of pliability. It is not only relatively independent of temporal rhythms, it is pliable both in the objects towards which it may be directed and in its modalities of expression.

(Berger and Luckmann 1966:67)

Sexuality has therefore become “a property of the individual” and “a means of forging connections with others on the basis of intimacy” (Giddens 1992:75).

Summary

As Foucault (1998:33) explained:

We are dealing less with a discourse on sex than with a multiplicity of discourses.

Early dominant discourses in Western society have portrayed sex as an involuntary biological instinct (Kinsey et al 1953; Kinsey et al 1948), with heterosexuality and vaginal intercourse being perceived as natural (Ellis 1913; Kinsey et al 1953; Kinsey et al 1948). Masturbation has been considered harmful (Ellis and Symonds 1897) and has been portrayed by influential authors (Kinsey et al 1953; Kinsey et al 1948; Masters and Johnson 1966) as a substitute for the ‘real thing’.

Throughout the 20th century, there has been a move towards a cultural understanding of sexuality (Gagnon 2004; Gagnon and Simon 2005). It is increasingly recognised that sexuality is a historical and social construct (Giddens 1992) that has been regulated by religious, medical and legal systems (Foucault 1998).

Research has exposed the cultural misconception that women are inherently less sexual than men (Masters and Johnson 1970), and the pattern of dominant-male and submissive-female has come to be recognised as a social construct (Coveney et al 1984; Ford and Beach 1952; Gagnon and Simon 2005; Jackson 1978; Jeffreys 1984; Plummer 2005). Despite this, dominant discourses that upheld western notions of an honourable male sexual vitality, and a dishonourable female sexuality (Masters and Johnson 1970) are likely to have prompted men to be the active partner sexually, and women to adopt the passive, submissive role.

Part 2 ~ Sexuality as experienced in terminal illness

Over the last 25 years, there has been a sporadic trickle of articles in healthcare journals that focus on sexuality in people living with a life-limiting illness. Most of these are opinion or discussion papers that validate sexuality as part of life that does not cease when someone is dying (Caruso-Herman 1989; Cort et al 2004; Farkas 1992; Leviton 1978; Monroe 1999; Nyatanga 2012; Redelman 2008; Rice 2000; Taylor 1983; Wells 2002; Woodhouse and Baldwin 2008). Some authors have described case studies or examples from their own clinical practice to support these views (Avens 1986; Gianotten 2007; Gilley 1988; Laury 1987; Monroe 1999; Rothenberg and Dupras 2010; Yaniv 1995) or have presented examples from autobiographical works (Wickett 1986).

Many of these authors considered sexuality to involve more than sexual behaviour, though stated that this aspect of sexuality can remain important for some couples nearing end of life (Gilley 1988; Laury 1987; Leviton 1978; Monroe 1999; Stausmire 2004; Wasow 1977; Wells 2002; Wickett 1986). Aitken (2009) has suggested that people's perceptions of themselves as sexual beings may change with a life-limiting illness, and the importance of physical closeness or touch has been emphasised (Avens 1986; Cagle and Bolte 2009; Caruso-Herman 1989; Cort et al 2004; Gilley 1988; Hordern and Currow 2003; Laury 1987; Monroe 1999; Shell 2008; Taylor 1983; Wells 2002; Wickett 1986; Yaniv 1995). It has also been argued that expressions of sexuality are influenced by appearance (Nyatanga 2012; Taylor 1983), body image and self-esteem (Cagle and Bolte 2009; Caruso-Herman 1989; Cort et al 2004; Laury 1987; Shell 2008; Wells 2002; Wickett 1986; Yaniv 1995).

Sexuality in people nearing end of life has been described as a means of giving and receiving affection (Avens 1986; Farkas 1992; Gilley 1988; Laury 1987; Wells 2002). This suggests that sexuality involves the expression of emotion (Wickett 1986), and is a means of communication (Hordern and Currow 2003; Redelman 2008). To summarise these views:

[Sexuality] is not simply the desire to have sex, it is the need to be held, to be intimate and ultimately to feel loved.

(Wells 2002:121)

Authors have recognised that the expression of sexuality is impeded in in-patient units by a lack of privacy (Avens 1986; Laury 1987; Wickett 1986), and others have advocated a pro-active approach in discussions with patients, arguing that the responsibility of addressing sexuality lies with healthcare professionals (Cagle and Bolte 2009; Cort et al 2004; Gianotten 2007; Hordern and Currow 2003; Monroe 1999; Stausmire 2004).

The (American) National Consensus Project for Palliative Care (2009) endorses sexuality as an important area of practice. More recent healthcare textbooks have recognised the importance of sexuality for people receiving palliative care (Gamlin 2005; Grigg 2002; Watson et al 2005; White 2003) and those who are dying (Monroe and Sheldon 2004; Searle 2002), but there is a paucity of research evidence to guide healthcare practice. Literature reviews have described a dearth of research that relates to people no longer receiving curative treatment (Blagbrough 2010; Cagle and Bolte 2009; Stausmire 2004; Wells 2002). Unfortunately, because some of these authors gave no indication of their search strategy (Cagle and Bolte 2009; Stausmire 2004; Wells 2002), it is impossible to say whether or not they overlooked relevant research. Blagbrough (2010) did provide some detail, but only used one search engine and imposed geographical limitations in the inclusion criteria⁵.

I therefore undertook a literature search of several databases: CINAHL (Cumulative Index of Nursing and Allied Health Literature), PubMed, PsycINFO and IBSS (International Bibliography of the Social Sciences) in order to identify research in this area. My search used the Boolean operators (OR and AND) to combine 'sexuality' OR 'intimacy' AND 'terminal*' OR 'dying' OR 'end of life' OR 'life limiting'. I searched the reference lists of all the articles I found for secondary sources, and also searched these reference lists for tertiary sources⁶. I found opinion papers going back over 40 years⁷, but only identified nine primary research studies (these are itemised in Table 1).

⁵ Blagbrough's (2010) literature review was restricted to studies undertaken in Australia, America, Canada and Europe.

⁶ I limited my search to papers published in English, and only excluded HIV because this is now considered to be a chronic illness rather than a life-limiting illness (Scandlyn 2000). I imposed no other exclusion criteria.

⁷ The oldest article was by Schon (1968).

Table 1: Research studies identified through searching the literature

Author	Year	Country	Research design	Focus	Sample	Method
Lion	1989	USA	Naturalistic inquiry	Experiences of sexuality in the dying	10 dying patients and 11 partners recruited from hospice services	No detail provided in the abstract, and the thesis was unavailable
Ananth et al	2003	England	Quantitative	Prevalence and nature of sexual dysfunction	50 patients with cancer from palliative care clinics and 50 from oncology. Also, 50 patients matched by age and gender from general practice	Completion of a pre-tested measure of sexual function and satisfaction
Lemieux et al	2004	Canada	Naturalistic inquiry	Meaning of sexuality	10 cancer patients from hospice and palliative care services	One-to-one semi-structured interviews
Hordern and Street	2007a; 2007b	Australia	Reflexive inquiry	Communication between patients and healthcare professionals about changes in intimacy and sexuality	50 patients with cancer from oncology and palliative care services	One-to-one semi-structured interviews

Hawkins et al	2009	Australia	Critical realism	Subjective experiences of sexuality and intimacy	156 partners of people with cancer	Postal survey followed by qualitative interviews with a purposive sample of 20
Matzo and Hijjazi	2009	USA	Mixed methods	Issues and concerns about sexual health	15 hospice patients with cardiac disease / cancer / multiple sclerosis	One-to-one interviews to gather qualitative data following completion of a validated QOL tool
Rothenberg and Dupras	2010	USA	Qualitative	Difficulties experienced in the sex lives of terminally ill patients	Terminally ill patients and partners attending sexology consultations	Reflection on case studies from clinical practice
de Vocht	2011	Netherlands	Hermeneutic phenomenology	Impact of cancer and cancer treatment on sexuality and intimacy	15 patients and 13 partners recruited via cancer support and rehabilitation groups	Mixture of one-to-one and coupled semi-structured interviews
Vitrano et al	2011	Italy	Quantitative	Attitudes and feelings about sexual behaviour	65 patients with 'advanced cancer' recruited from a palliative care unit and an acute pain relief unit	Structured face-to-face interviews on sexual behaviour and satisfaction

One of these studies was an American PhD study (Lion 1989), which was unavailable from inter-library loans⁸.

Rothenberg and Dupras (2010) described a qualitative study to understand the difficulties experienced by terminally ill patients and their partners in relation to their sexual life. They found that both patients and their partners wanted “to touch and be touched both physically and emotionally” (Rothenberg and Dupras 2010:150), and that people needed opportunities to grieve the losses experienced in their sexual life. However, as their data consisted of case histories from sexology consultations, their sample only involved people presenting with sexual problems. Their assertion that partners became increasingly isolated from each other during life-limiting illness, could merely reflect the bias within their sample.

Despite the lack of evidence of robustness in their article⁹, Rothenberg and Dupras (2010) have highlighted an important consideration for practice: partners did not know how to raise their own concerns with hospice staff. Rothenberg and Dupras (2010) have also raised an otherwise overlooked issue, that of sexuality in carers. One woman described losing interest in sex with her husband because of the responsibilities of caring for her dying mother (Rothenberg and Dupras 2010). This suggests that the ramifications of life-limiting illness on sexuality can extend beyond the patient and their partner.

Vitrano et al’s (2011) Italian study consisted of 40 female and 25 male patients with ‘advanced cancer’ recruited from a palliative care unit and an acute pain relief unit. These researchers defined ‘advanced cancer’ as incurable, but stated that this “does not mean that a patient is already terminally ill” (Vitrano et al 2011:198). All of the participants were in a partnered relationship, but the age range was not stated.

Vitrano et al (2011) described their study as ‘prospective’, but asked participants (in face-to-face interviews) to rate their sexual interest, the frequency of sexual intercourse, their sexual satisfaction and the importance of “the emotional aspects of sexuality” (Vitrano et al 2011:202) at the time of the interview compared to when they were first diagnosed.

Unfortunately, this study sheds little light on people’s experiences because the

⁸ This PhD was typed using a type-writer, so the author did not have an electronic copy she could email me (Lion, personal correspondence).

⁹ They gave no detail of the selection criteria used when deciding which case histories to include in their study, and did not provide any extracts from the consultations for the reader to assess the trustworthiness of their findings.

researchers did not use a validated questionnaire and used ambiguous language in their questions.

However, their study does have some useful findings. Although retrospective data can be unreliable, it is notable that only 48.5% of the sample still had sexual intercourse at the time of the interview, compared to 98.5% who reported having intercourse before their illness (Vitrano et al 2011). The unmet sexual needs in this population were evident as 86.4% of participants indicated that they would like to speak with a healthcare professional about their concerns.

Also interested in sexual function after cancer, Ananth et al (2003) attempted to determine the prevalence and nature of sexual dysfunction in cancer patients. They recruited 150 patients in total, with equal numbers from an oncology clinic, an outpatient palliative care clinic, and patients matched by age and sex from general practice attendees. It is interesting that 90% of the patients from the palliative care clinic who were invited agreed to participate, compared to only 53% from the oncology clinic. However, as patients attending oncology appointments are likely to be involved in treatment regimes, no inference can be made from this regarding the importance of sexuality in their lives.

Ananth et al (2003) developed a self-report measure of sexual function, and piloted it for test and re-test reliability. Participants were asked to rate the frequency of their sexual activity, the strength of their sexual and emotional relations, as well as their general sexual satisfaction before and after the disease onset. The patients recruited from the palliative care clinic reported significantly more sexual dysfunction than either of the other two groups. In comparison with the healthy controls, significantly more patients in both cancer groups wanted the opportunity to discuss sexual concerns with a healthcare professional.

There have been two other primary research studies on sexuality where the sample groups have included patients receiving 'palliative care' (de Vocht 2011; Hordern and Street 2007a; Hordern and Street 2007b). 'Palliative care' was once defined as care that is given when a disease is no longer responding to curative treatment (Saunders and Baines 1983). However, the term is now recognised as a much broader concept that encompasses symptom relief for patients *throughout* the course of their illness (Addington-Hall 2005; Ahmedzai and Walsh 2000), and not necessarily at end of life (Addington-Hall 2002). It is therefore unclear whether participants in receipt of palliative care in the studies by Hordern and Street (2007a; 2007b), and de Vocht (2011) had life-threatening or life-

limiting cancer (i.e. whether or not they were terminally ill). Nonetheless, their studies have highlighted the importance of sexuality in people of all ages.

Hordern and Street (2007a; 2007b) explored constructions of sexuality and intimacy from the perspective of patients with cancer in Australia. Using a purposive sampling strategy to ensure adequate representation of people with breast, prostate, lung and bowel cancer (reported by them to be the most common cancers in Australia), they recruited 50 patients from both oncology and palliative care services. Their patient sample consisted of people aged 22-88 years (44% were over the age of 60). Using semi-structured interviews, they asked participants to define sexuality and intimacy, and to describe an experience when they had had an opportunity to discuss issues relating to sexuality or intimacy with a healthcare professional. They found that, irrespective of age, gender or type of cancer, patients described an altered sense of self, with changes in sexual domains. Although a useful study in identifying unmet needs, their study is limited because it did not consider the experiences of partners.

Recognising this research gap, Hawkins et al (2009), surveyed 156 partners of people with cancer in Australia and found that 84% of partners of people with a sexual cancer (e.g. prostate, ovary, breast) and 76% of partners with a cancer that did not affect the sexual organs described a negative impact on their sexual relationship. Using qualitative interviews with 20 of the survey respondents who had reported that the cancer had impacted on their sexual relationship, Hawkins et al (2009) endeavoured to understand their subjective experiences. In semi-structured interviews, participants were asked to describe the changes to their sexual relationship and if their role as a carer had impacted on this.

Partners described a cessation, reduction or re-negotiation of their sexual relationship (Hawkins et al 2009). Some experienced a sudden cessation of their sexual life, which was also accompanied by a loss of intimacy (Hawkins et al 2009). In contrast, some partners described maintaining intimacy through physical closeness until death:

I remember the morning he died, I remember cuddling him all night ... Just to have your, to have your arm around him was just so, so good.

(Hawkins et al 2009:274)

Although cancer treatments (including surgery, chemotherapy and hormonal treatment) were cited as the main cause of the changes to their sexual relationship, partners also described their own exhaustion and a loss of sexual interest due to worry and a change in role (becoming a carer). Others described a “repositioning of the person with cancer” as a ‘patient’ or as a ‘child’ (Hawkins et al 2009:275). These changes led to feelings of remorse, rejection, self-blame and a sense of loss. Like the patients in Hordern and Street’s (2007a; 2007b) study, many of these partners (20% of the 156 surveyed) also described unmet needs, where healthcare professionals had failed to acknowledge the impact of the cancer on their sexual life.

It is clear from these examples that some of the participants in their study were bereaved at the time of the interview, and the experiences they were describing occurred in the knowledge of the illness being life-limiting. However, it is difficult to tease out from their research papers which of the findings pertain to people with a life-limiting illness (as opposed to curative cancer).

In the Netherlands, de Vocht (2011) also recognised the importance of acknowledging the sexual lives of partners. She recruited patients and their partners via cancer support groups and cancer rehabilitation groups. Using a mixture of one-to-one and joint interviews, she interviewed 15 patients with cancer and 14 partners. Like others (Hordern and Street 2007a; Hordern and Street 2007b; Vitrano et al 2011), de Vocht (2011) also found unmet needs. Patients and their partners wanted professionals to be proactive in discussing sexuality, and to provide practical information and suggestions. More importantly, they wanted to be treated as an individual that mattered; they wanted healthcare professionals to attend to their lived experience, and be willing to listen.

Unfortunately, as 13 of the patients interviewed by de Vocht (2011) were women, her study provides limited insight into the experiences of male patients and their partners. Also, because the focus of her study was on ‘cancer and palliative care’, it is unclear whether the participants were living with life-threatening or life-limiting illness¹⁰.

A slightly older Canadian study conducted by Lemieux et al (2004) sought to ascertain the meaning and importance of sexuality for patients with cancer. Their sample of 10 patients was recruited from a hospice, an acute hospital palliative care unit, and palliative home

¹⁰ It is not possible in her thesis to distinguish between participants in this way.

care services. As their exclusion criteria included a life expectancy of less than two weeks, and eight of the participants died within 12 weeks of being interviewed (two of these died within a week), it suggests that their sample of 'palliative care' patients all had life-limiting (terminal) disease.

Using a pre-determined interview guide, Lemieux et al (2004) interviewed 10 patients with cancer in partnered relationships; their ages ranged from 44 to 81 years. The interview questions focussed on the meaning and expression of sexuality, sexuality and quality of life, barriers to sexuality in institutional care, and discussing sexuality with healthcare professionals. Participants described a decreased frequency of sexual intercourse since their diagnosis, with more of an emphasis on emotional attachment. Unfortunately, the researchers in this study did not explore how people managed this transition within their coupled relationship.

Sexuality was expressed through "‘meaningful’ eye contact" (Lemieux et al 2004:634) and companionship, as well as kissing, hugging and holding hands. Barriers to physical and emotional intimacy in hospital and hospice settings included lack of privacy. This was described by one participant:

While I was in the hospital and I was in that group of four or five patients there ... I did not show my intimacy. We still held hands, but I would not try to grab her and kiss her and cuddle ... But once we got our private room, things changed. She was sitting on the bed, we were holding, kissing, hugging ... I could be more open, I could let my feelings go (crying) ... in the private room, you can open up and be more yourself.

(Lemieux et al 2004:633)

The study also highlighted the importance of protected time for couples in in-patient settings that was free from the intrusion of staff:

I think that there's also a need for putting a priority on couples spending time together ... It should be quality time and even if you had to shorten the visiting hours ... there's an hour a day, two hours a day, that it's just strictly straight forward family time. And you and your family get together and we promise not to bring a pill or do a blood test during that time period.

(Lemieux et al 2004:633)

Although all of the participants in their study felt that sexuality should be discussed routinely as part of their care, it is feasible that the convenience sample only included people who were comfortable discussing this aspect of their life, so no firm conclusions can be drawn from this particular finding. However, all of these studies have shown that healthcare professionals failed to recognise and meet people's needs in relation to sexuality (de Vocht 2011; Hawkins et al 2009; Hordern and Street 2007a; Hordern and Street 2007b; Lemieux et al 2004; Rothenberg and Dupras 2010).

This finding was echoed in Matzo and Hijjazi's (2009) mixed-methods study to ascertain hospice patients' issues and needs regarding sexual health. The researchers defined 'sexual health' as comprising aspects of "healthy human sexuality" (Matzo and Hijjazi 2009:274), which included body image, sexual identity, intimacy, sexual function and relationships. Using the WHO-QOL-100 assessment tool (World Health Organisation 1998), they interviewed 15 patients (recruited from five hospices), with ages ranging from 37 to 97 years. Participants were asked to expand on their answers to each question in the assessment tool in order to gather further understanding about their needs.

Their study showed that interest in intimacy and sexual expression was independent of age, and continued with late-stage disease. None of the patients had been asked, during either their illness or hospice admission, about their sexuality or intimacy needs, yet several of the men reported erectile dysfunction that they wanted resolved. Their reasons for not raising the subject themselves included not knowing if it was appropriate to do so and being uncertain how to. One woman recommended that healthcare professionals:

... don't just focus on my body, but help with the relationship.

(Matzo and Hijjazi 2009:279).

Unlike the other studies identified in this review, 60% of their sample had cardiac disease (n=9), while the remainder had cancer (n=5) and multiple sclerosis (n=1). The article does not specify whether or not they were terminally ill, but as they were recruited via hospices, it is perhaps reasonable to infer this. It is notable that all but two (Matzo and Hijjazi 2009; Rothenberg and Dupras 2010) of the research studies that I have been able to identify that considered sexuality and intimacy in people with life-limiting illness focussed exclusively on patients with cancer (de Vocht 2011; Hawkins et al 2009; Hordern and Street 2007a; Hordern and Street 2007b; Lemieux et al 2004). This suggests a lack of recognition of sexuality and intimacy as issues for people with other conditions.

Sexuality as experienced with disability

Authors are in agreement that there is a tendency for people who are disabled to be asexualised (Adams 2000; Kaufman et al 2003; Webster and Heath 2002). With regard to people with learning disabilities, issues of consent and the importance of considering the potential for exploitation and abuse are dominant discourses in relation to sexuality (Adams 2000; Cooper and Guillebaud 1999; Keighley 2002). However, vulnerability should not be the sole focus; people with learning disabilities have an equal right to express their sexuality through sexual relationships (Royal College of Nursing 2000).

The asexualisation of people with physical disabilities is evident in the absence of condoms and tampons in disabled toilets (Brown et al 2000) and has been portrayed through a variety of genres. For example, Connie's husband, in *Lady Chatterley's Lover* (Lawrence 1960), was impotent as a result of a war injury and therefore "could never be a husband to her" (Lawrence 1972:3). The inference here is that, to be a husband, a man had to be able to have sexual intercourse with his wife. Sir Clifford's impotence rendered their relationship an incomplete marriage, and him an incomplete man.

There is little written about the sexuality of people with congenital disabilities. One particular narrative, by a 22-year-old man with Duchenne muscular dystrophy¹¹, highlighted the difficulties people with disabilities experience in forming relationships. Wallis (2007) came to realise that the only way he would be able to experience sex was to pay for a sex worker:

University is where many young people make their first serious forays into the world of relationships and sex. For the most part my attempts to form friendships or even to strike up conversation were rebuffed. I felt like a foreigner in a new country, speaking a language no one understood. The idea of meeting girlfriends or even forming friendships with them, which I had hoped would be possible in this new environment, began to seem unachievable. Physical intimacy or, dare I say it, sex seemed completely out of the question ... Although I had always hoped that sex would be just one part of a close relationship, I began to accept that this might not happen for me. I wanted to know what sex was like even if this meant that I had to pay someone.

¹¹ Duchenne muscular dystrophy is a degenerative, disabling condition that is life-limiting.

With the support of the hospice where he received respite care, Wallis (2007) arranged for a sex worker to visit him at home.

Looking back, I am pleased I had the tenacity and commitment to see it through. The experience, while not emotionally fulfilling, gave me confidence and a sense that I was not missing out ... I regret that I couldn't be like everyone else and share a first sexual relationship with someone I knew and loved ... I do not think I will necessarily choose to repeat the experience, although I have not ruled it out. Sexuality is more than just sex: it is about feeling attractive and attracted to others without feeling guilty or peculiar about something that is intrinsically part of being human. A cliché, I know, but it is about feeling comfortable in your own skin. My experience taught me a lot ... But it did not give me what I most want. I continue to hope that I may be able to establish a relationship with the right person. The same as any other "dude", as my older brother Tom would say, I want to be able to hold hands with someone, to love and be loved.

(Wallis 2007)

The importance of an emotional relationship is highlighted here. Wallis (2007) described a sexual experience that was “not emotionally fulfilling”. He had achieved his goal of experiencing sex, but it did not give him what he most wanted - a relationship. This is further illustrated in two recent films; *Wish 143* (Barnes 2009) and *The Be All and End All* (Be All Films Ltd 2010). Both of these films portrayed the experiences of teenage boys who, unlike Wallis (2007), were not disabled; they were dying of cancer and wanted to experience sex before they died. These story-lines also portrayed having to resort to sex with a prostitute to realise their wish. Although the focus of these fictional films was on sexual activity, the story-lines effectively portray that sexual intercourse alone falls short of a loving, intimate relationship. As one boy said to the sex worker, “can you just hold me?” (Barnes 2009).

Although these films were fictional accounts, living with unfulfilled desire is a common finding across studies of people with disabilities in America (Ostrander 2008a; Ostrander 2008b) and Greece (Sakellariou 2006; Sakellariou and Sawada 2006). As one man with a spinal cord injury explained:

The desire is still there. Absolutely. And with no release...I can indulge in foreplay and all sorts of touchy stuff, but have no ability to reach orgasm or ejaculate. The

absence of that overwhelming sensation of pleasure and release afterwards is something I never, ever, have got over.

(Ostrander 2009:14)

Shakespeare et al (1996) have expressed concern that medical, psychological and sexological academics have neglected positive discourses on sexuality in disability. The purpose of their book, *The Sexual Politics of Disability: Untold Desires* presents what they believed to be a more balanced view of the experiences of disabled people by discussing not only the sexual oppressions they experience, but also presenting positive, fulfilling experiences.

These positive experiences have been described as “an unexpected finding” in a study with women who have ‘Lupus’ (systemic lupus erythematosus¹²) (Karlen 2002:191). Some participants described considerable benefits in “sexual self-acceptance, expression and pleasure” (Karlen 2002:204), while others reported improved relationships even though they did not always feel as sexually satisfied as they would like.

Similar positive experiences are also evident in studies that have shown that, despite the limitations imposed by their physical disability, many men describe satisfying and meaningful sexual lives (Ostrander 2008a; Ostrander 2008b; Sakellariou and Sawada 2006). Because these men also spoke of experiencing unmet sexual desire, the meaning that they attributed to their sexual satisfaction would appear to exceed merely orgasmic pleasure.

Some authors have recognised that the impact of disability on partners tends to be overlooked (Cooper and Guillebaud 1999; Ostrander 2009; Webster and Heath 2002). Disability can impact upon economic and social roles within relationships, and the altered balance may affect sexual roles and sexual expression (Cooper and Guillebaud 1999). The provision of physical care to one’s partner may also have an impact. For example, Roe and May (1999) found that having to clean up after incontinence can be sexually off-putting for partners. In contrast, Sherman (1998) suggested that spouses might feel duty bound to meet their partners’ sexual needs and would not allow incontinence to interfere with this. However:

¹² Systemic lupus erythematosus is an incurable disease of the immune system.

It is a very big step to switch from nurse/carer by day to a lover by night.

(Cooper and Guillebaud 1999:12)

This concurs with some of the participants in Hawkins et al's (2009:275) study (described previously) where partners of people with cancer described "repositioning" their ill partner as a child or as a patient, no longer a lover (Hawkins et al 2009:275).

As discussed previously, however, there can also be positive aspects. Disability can bring with it increased opportunities for sexual experimentation (Ostrander 2009; Shakespeare et al 1996) and some people with an acquired disability believed they became better lovers following the injury because they became more attentive to their partner's sexual needs (Ostrander 2009). This is supported by research with partners of people with spinal cord injuries, who reported greater sexual satisfaction (Kreiter et al 1994).

There appears to be significantly more research on the experiences of people with spinal cord injuries in relation to sexuality than there is on disabilities such as multiple sclerosis and motor neurone disease (MND). I have wondered if it is because spinal cord injury tends to affect younger adults and is not life-limiting (suggesting a presumption of asexuality in older people). However, as sexual function is not directly affected in MND (Wasner et al 2004), it is feasible that this might partially account for the disparity in research interest. If this is the case, it would suggest a functional view of sexuality.

Sexuality as experienced with motor neurone disease

Because end of life care should not focus exclusively on people with cancer (this is endorsed by the Department of Health 2008), I undertook a further search of the same databases¹³ using 'sexuality' paired with 'motor neuron*' OR 'MND' OR 'amyotrophic lateral sclerosis'. This search identified two research papers, both reporting studies that had been undertaken in Germany (Kaub-Wittemer et al 2003; Wasner et al 2004).

Kaub-Wittemer et al (2003) were interested in quality of life in two patient groups: those with non-invasive ventilation (NIV)¹⁴ and those with tracheostomy ventilation (TV). They developed a postal questionnaire and asked participants to complete the questionnaire

¹³ These were CINAHL (Cumulative Index of Nursing and Allied Health Literature), PubMed, PsycINFO and IBSS (International Bibliography of the Social Sciences).

¹⁴ Non-invasive ventilation (NIV) forces air into the lungs at high pressure in order to force chest expansion and enable breathing (Talbot and Marsden 2008). It involves wearing a mask, firmly secured to the face, which is connected to a small machine.

independently from their partner. Thirty-two couples with NIV and 21 couples with TV took part, as well as one additional patient with NIV.

These researchers were surprised to find that a significant proportion of people with non-invasive ventilation (56%) and tracheostomy ventilation (43%) rated sexuality an important issue. Notably, 31% of the 32 patients with NIV said that sexual activity was still possible, compared to only three of the 20 patients with tracheostomy ventilation. However, given that 72% of the NIV group and 91% of the TV group were men, gender differences in sexual roles might account for the loss of sexual activity within these participants' relationships. The study's response rate of 52% leaves further questions unanswered, as it is unclear how representative the sample was. Also, the authors do not indicate whether the questionnaire had been validated, further limiting the strength of their findings.

The second German study was undertaken by Wasner et al (2004). Patients attending an MND clinic and their partners were (separately) asked to rate their sexual interest and sexual behaviour, currently as well as before the onset of MND. Twenty-six couples¹⁵ took part, as well as seven single patients and three partners. The average age of the sample was 65 years (ranging from 48 to 80 years). In this study, both patients and partners reported a substantial decline in sexual interest and a moderate decline in sexual activity. There was also a significant increase in self-reported sexual problems (62% of patients and 75% of partners compared with 19% and 20% respectively before the onset of MND). Their current sexual problems were largely attributed to reduced libido and weakness or passivity. It is important to note, however, that 20% of patients and 11% of partners reported improvements in their sexual relationship. Only 13% of these participants reported having been asked about sexuality by their doctor.

These two studies have shown that sexual expression is important for people with MND (Kaub-Wittermer et al 2003; Wasner et al 2004), and confirms the findings of studies by Jacobs et al (2000) and Demirkiran et al (2006), which found that sexual problems were also of concern for people with other neurological conditions (Parkinson's disease and multiple sclerosis respectively). However, these studies focused on sexual behaviour and sexual function, and there have been no qualitative studies considering how MND affects people's sexuality and what this means for people.

¹⁵ The authors did not specify whether these couples were heterosexual or represented a broader spectrum of relationships.

Summary

Despite the numerous opinion papers that have been published spanning over 40 years, sexuality and intimacy in life-limiting illness is an area of research that has received very little attention. The few studies that have been undertaken have tended to focus exclusively on the experiences of people with cancer (Ananth et al 2003; de Vocht 2011; Hordern and Street 2007a; Hawkins et al 2009; Lemieux et al 2004; Vitrano et al 2011), and few have considered the experiences of partners (de Vocht 2011; Hawkins et al 2009).

The only English study that has been undertaken in this area limited its focus to sexual function and sexual satisfaction (Ananth et al 2003). Findings from qualitative research in other countries have shown that people experience an altered sense of sexual self (Hordern and Street 2007a; Hordern and Street 2007b), and changes to their sexual relationship (Hawkins et al 2009; Vitrano et al 2011) that are independent of age (Matzo and Hijazi 2009; Hordern and Street 2007a; Hordern and Street 2007b), gender and cancer type (Hordern and Street 2007a; Hordern and Street 2007b). However, the experiences of people who are not heterosexual have rarely been acknowledged¹⁶.

Unfortunately, because many of the qualitative studies did not draw a distinction between cancer and palliative care (Hordern and Street 2007a; Hordern and Street 2007b; Lemieux et al 2004; de Vocht 2011), it is unclear to what extent their findings relate to people who have life-limiting illness.

Conclusion

Definitions of sexuality in the healthcare literature consider sexuality to include more than sexual behaviour (Gamlin 2005; Odey 2009; Rice 2000; Royal College of Nursing 2000; Peate 2010), though many of the narratives discussed here would suggest otherwise. Sexual behaviour does not only involve physical acts, but also involves social and psychological meaning (Gagnon and Simon 2005). Sexuality is “a multi-dimensional, fluid, dynamic construct ... meaning different things to different people” (Peate 2010:239). What is not clear is what sexuality means to people living with a life-limiting illness. Further

¹⁶ Lemieux et al (2004) did acknowledge this as a limitation of their study. Their intention had not been to limit their sample to heterosexuals, but recruitment was restricted by the sample population available at the time of the study.

research is therefore needed to understand the experiences of sexuality and intimacy for patients who are terminally ill and their partners. Only then can we begin to consider a role for healthcare professionals in addressing this aspect of people's lives.

Chapter 2: Philosophical perspectives

... I believe I will never quite know.
Though I play at the edge of knowing,
truly I know
Our part is not knowing...

(Oliver 2004:5)

Introduction

The limited empirical research on sexuality amongst those with life-limiting illnesses suggested a need for a qualitative research design in order to explore what it means from the perspective of patients and partners of patients. I selected a phenomenological methodology because the primary concern of phenomenology is the nature and meaning of human experience:

Phenomenology offers a means of attending to human experiences... and the possibility of understanding such experiences in a way that can change how we nurse.

(Madjar and Walton 1999:190)

In order to 'get behind the label' (Walton and Madjar 1999) of the scientific conceptualisation of sexuality, phenomenology emphasises the centrality of human experience (Munhall 1989). Thus the focus of this research is the subjective experience of sexuality and intimacy for patients and partners of patients living with life-limiting illnesses.

There are many interpretations of phenomenology, ranging from descriptive to interpretive. Some have advocated that phenomenology should only examine objective phenomenon (Crotty 1996), while others support the exploration of feelings and subjective experiences (Benner 1994; Diekelmann and Ironside 2006; Munhall 1989). As the focus of nursing care is the subjective reality of human experience, it was more appropriate to adopt an approach that incorporates the exploration of subjective experiences that includes individuals' thoughts and feelings. Therefore I selected Heideggerian hermeneutic phenomenology as the appropriate methodology for this study.

Phenomenology has been adopted by many nurse researchers (Benner 1984; Chan et al 2002; Kavanagh 2007; Sloan 2002). However, there has been considerable confusion in the methods used, with many researchers failing to recognise the variations between the different phenomenological perspectives (Koch 1995). This comes, in part, from the interchangeable use of the terms 'phenomenology' and 'hermeneutics' (Koch 1995), and is compounded by an assumption by some authors that all phenomenological research is reliant upon processes such as 'bracketing' and 'member checking'.

This chapter explains a distinction between methodological approaches that draw upon Husserl's descriptive phenomenology and Heidegger's hermeneutic (interpretive) phenomenology. Heideggerian hermeneutics is presented as an appropriate methodology for this research study which examines the meaning of sexuality and intimacy in the lives of patients and partners of patients living with a life-limiting illness.

What is phenomenology?

Phenomenology is the study of human experience (Polkinghorne 1989). The purpose of phenomenological research is to bring into awareness and examine the taken-for-granted aspects of everyday life (Powers and Knapp 1995). The word 'phenomenon' comes from the Greek *phaensthai*, to flare up, to show itself or to appear (Moustakas 1994). The motto of phenomenology is therefore '*Zu den Sachen*', which means both 'to the things themselves' and 'let's get down to what matters' (van Manen 1990:184).

The philosopher, Edmund Husserl (1859-1938) is recognised as the founder of the phenomenological movement (Koch 1996). Husserl introduced the concept of the lifeworld [*Lebenswelt*], the world of lived experience, and described this lifeworld as "the world of immediate experience", the world as experienced in the "natural primordial attitude" (Husserl 1970:103-186). Husserl's (1962) emphasis was on revealing the 'essence' of phenomena, and Husserlian phenomenologists seek to study things that are 'pre-given', before "critical or theoretical reflection" (van Manen 1990:182).

Epoche is a Greek word, meaning to refrain from or suspend judgement (Encyclopaedia Britannica, no date). In the *Epoche*, everyday understandings are set aside, so that phenomena can be examined from a naïve perspective (Moustakas 1994:33). In order to achieve this, Husserl (1962) derived phenomenological reduction; this approach requires a

suspension of judgement (Husserl 1962) in order to understand ‘the things themselves’ (van Manen 1990:184).

Husserlian phenomenologists therefore set out to “meet the phenomenon as free and as unprejudiced as possible” (Dowling 2005:132). This stance defends the objectivity of interpretation and proposes that we should ‘bracket’ off our own subjective experiences in order to retain an objective view of another’s experiences. The purpose of this is to ‘suspend belief’ in order to see the phenomenon in its ‘uncontaminated’ state. This is often interpreted as a fundamental strategy in phenomenology (Crotty 1996; Groenewald 2004), and has been argued by some nurse researchers to be a strategy for enhancing rigour (Knaack 1984; Oiler 1982). Although Oiler (1982) recognised that it is impossible to be totally free from bias, she argued that it is necessary, and indeed, possible to control it. However, this focus upon objectivity fails to recognise any inherent subjectivity.

Differing approaches to phenomenology in nursing research

Crotty (1996) argued that many nurse researchers who purported to use phenomenology did not actually do so as their work did not espouse the constructivist epistemological position that Husserl regarded as essential to phenomenology. A number of authors have discussed the difference between what they called ‘traditional’ (‘European’) and ‘American’ phenomenology (Caelli 2000; Silverman 1987), yet failed to distinguish between Heideggerian and Husserlian phenomenology, categorising them both under the broad brush of ‘European’.

Caelli (2000) identified two distinct characteristics of American phenomenological research. Firstly, the American research generally does not seek to uncover pre-reflexive experience, as it includes participants’ thoughts and feelings about the experience in both the collection of data and its analysis. Secondly, analysis describes participants’ experiences within the context of their culture, rather than attempting to search for universal meanings. This approach is consistent with that of American phenomenologists such as Diekelmann and Ironside (2006) and Benner (1984)¹⁷.

Paley (1997) suggested that Husserl’s work has been misinterpreted by such researchers, and Spiegelberg (1982) argued that, if research is to be correctly termed

¹⁷ These researchers align themselves with the philosophy of Heidegger (1962), recognising that all experience (and therefore all research data) is context dependent.

phenomenological, it should contain the common core; the search for the objective reality of the things themselves. Caelli (2000), however, argued that the differences that have arisen in American phenomenology need not have arisen from confusion, but represent new ways of applying phenomenological philosophy, establishing “clear and original paths” (Silverman 1987:6).

The problem with the explanations of Paley (1997) and Crotty (1996) is that they advocated that the researcher elicits pre-reflective experiences, “before we have thought about it” (Crotty 1996:53). This stance arises from the Husserlian notion of phenomenological reduction, to refrain from judgement (Husserl 1962) and hold in abeyance subjective experiences and theoretical constructs (Racher and Robinson 2002; Koch 1995). This approach requires that descriptions of experience be gleaned before they have been reflected upon (Caelli 2000). Whether it is possible to describe an experience prior to reflecting upon it is much debated; the very nature of describing a lived experience in language is, in itself, an interpretative process (van Manen 1990).

What is hermeneutic phenomenology?

Martin Heidegger (1889-1976), one of Husserl’s students, developed phenomenology beyond the ideas of his teacher. Although agreeing with Husserl’s declaration “to the things themselves” (Heidegger 1962:50), Heidegger, believed that it is impossible to describe without interpretation. He argued that human beings live ‘hermeneutically’ as we are constantly interpreting, finding significance and meaning in our worlds (Heidegger 1962).

The term ‘hermeneutics’ derives from Hermes, a messenger in Greek mythology who interpreted the words of the gods to the underworld (Healy 2011). Hermeneutics is therefore an interpretive approach (Schmidt 2006) and hermeneutic phenomenology is an interpretive rather than a descriptive process (Racher 2003).

Instead of enquiring about the objective reality of phenomena, Heideggerian hermeneutics seeks to understand the meaning of lived experience for the person (Caelli 2000). The question may still be, as Husserl (1962) advocated, ‘what is it like?’ yet the analysis involves a fusion between the experiences described by the participants with the experiences of the researcher (Koch 1996). Because ‘viewer’ and ‘subject’ are inseparable (Heidegger 1962), researchers cannot ‘bracket’ their pre-suppositions.

What is Being?

Heidegger's (1962) classic text, *Being and Time*, expanded phenomenological philosophy from epistemological questions to an ontological one concerning the nature of existence. Posing the primordial ontological question, 'What does it mean to Be?', Heidegger (1962) believed that there were many ways for humans to be in the world but the most significant was in being aware of one's own Being. This state is named 'Dasein' (Heidegger 1962), and distinguishes humans from other entities because Dasein is "the kind of being that is open to Being" (Krell 1993:32), capable of wondering about its own existence.

Being-in-the-world

Human existence and the world are inextricably linked. Dasein does not exist in isolation; its existential nature is always in relation to others (Heidegger 1962). Our everyday way of being-in-the-world is therefore one of engagement (Heidegger 1962), and our understanding of animate and inanimate entities is with reference to interrelated "systems of meaningfulness" (Sembera 2007:37).

Heidegger (1962) used the example of a hammer to explain how entities are understood in relation to each other. A hammer is understood in relation to its purpose of banging in a nail, and the nail is understood in its purpose of connecting two pieces of wood in order to construct a building. The building is understood in terms of the purpose it serves in keeping animals dry or in providing a home. Meaningfulness is therefore established in terms of its function and purpose: "in-order-to" (Heidegger 1962:98) and "towards-which" (Heidegger 1962:99).

This is exemplified further in the meaning of a bed:

A bed is a bed because of the meaning it holds for us; we might understand it as a place to sleep, or as a place to be intimate, or indeed as a place to die.

(Taylor and de Vocht 2011:1579)

For a tribesman who has never encountered a bed before, it might not be 'seen' in any of these ways; it might be understood as firewood for cooking or keeping wild animals away. It is the in-order-to and for-which that determine meaning (Heidegger 1962).

Although other entities are understood in terms of their function and purpose, this does not mean that other people are seen in the same way, for other people are understood in relation to Dasein:

The entity which is 'other' has itself the same kind of Being as Dasein. In Being with and towards Others, there is thus a relationship of Being [Seinsverhältnis] from Dasein to Dasein.

(Heidegger 1962:162)

Being-with is therefore an essential element of Being-in-the-world. Humans exist in a world of relationships with other Daseins as well as other entities: "existence is embedded in-the-world and our being-in-the-world cannot be separate from the world" (Mackey 2005:181).

However, when Dasein is absorbed in its concern towards others, it becomes subsumed by *das Man* ('the they') and is no longer authentically itself. Heidegger (1962) called this 'inauthenticity' [*Uneigentlichkeit*]. In this mode, Dasein is preoccupied with how it compares with other Daseins (Harman 2007). The "magnetic pull" (Taylor and de Vocht 2011:1580) of 'the they' compels us to laugh because 'they' laugh, or clap because 'they' clap.

Moment by moment, we are inauthentic, with the ever-present potential for authenticity (Taylor and de Vocht 2011). As Scott (2010:59) explained:

If I relate to myself as one is expected to do, if I see myself the way others see me, if I go along to get along, I make choices as though I were not my own life. I intend what they intend for me. We talk as one does.

In inauthentic mode, Dasein might remove 'excess' body hair because that is what 'they' (e.g. women) do. The everyday self of Dasein is subsumed into *das Man* (Heidegger 1962) and loses its authentic potential of choosing to choose (Cerborne 2006). To make the transition to 'authenticity' [*Eigentlichkeit*], a moment of disruption [*Angst*] is required (Heidegger 1962) to release Dasein from its fixed habits. In its authentic mode, Dasein has a glimpse of its mortality and the finitude of its own existence.

Being-towards-death

According to Heidegger (1962), death is an essential quality of what it is to be human. The nature of life and the nature of death are interwoven and inseparable. We can only

understand death because we experience life, and we can only understand life because we are mortal and will one day die.

Anticipation [*Vorlaufen*] is the authentic response to death. The literal translation of *Vorlaufen in den Tod* is “running ahead into death” (Wrathall 2005:69). Heidegger (1962) suggested that when we orient our lives towards death, we live authentically. In its awareness of death, Dasein recognises it is existentially separate from “the they” because death is our “ownmost” possibility (Heidegger 1962:307): “no one can take the Other’s dying away from him” (Heidegger 1962:284).

Death is therefore more than an event; it shapes our experiences. It is in facing one’s own death that Dasein is brought back from the fallen-ness of ‘the they’. Realisation of our own death makes us aware of our own possibilities for Being. This ‘possibility’ is not in the sense of being not yet real (as in possibly a hammer), or in the sense of what is *only* possible (as in postulating that it might snow in Sudan). The ‘possibility’ of death for Dasein is in the sense of potentiality; that which can be ~ a possibility that is not yet actualised.

The ‘ending’ which we have in view when we speak of death, does not signify Dasein’s Being-at-an-end [Zu-Ende-sein], but a *Being-towards-the-end* [*Sein zum Ende*] of this entity.

(Heidegger 1962:289. Italics in original)

To exist authentically, Dasein is not fixed upon death as an actual event, but sees death as a futural possibility. It is in recognising its being-towards-death and living into possibility that Dasein can reach its potential. This calls me to wonder how patients and partners of patients experience their world with one another when living with a life-limiting illness. What are the new possibilities for being?

Temporality

Heidegger (1962:39) considered Dasein to be temporally situated in the world, arguing that temporality is “the horizon for all understanding of Being and for any way of interpreting it”. Explaining this further, Mackey (2005:183) stated:

Temporality allows past, present and future to be experienced as a unity. The experience of this unity means that what is experienced in the present is coherent with what was experienced in the past and is expected to be experienced in the future, such that awareness of them is as one, in the present.

Past, present and future are therefore not discrete periods of time; temporality is not a series of self-contained 'nows' (Mulhall 2005) that separate present from future and past. The past and present are therefore related to the future in the threefold structure of Dasein's temporality. Because Dasein is able to be "at once ahead, behind and alongside oneself" (Mulhall 2005:161), temporality is the horizon for all understanding (Heidegger 1962) and "gives humans meaning" (Parsons-Suhl et al 2008:37). It is through our "living into possibility" that meaning is construed (Heidegger 1962:138).

People's current experiences of sexuality and intimacy are therefore influenced by their prior experiences and their anticipation of their future. As this study seeks to understand the meaning of sexuality and intimacy for individuals living with a life-limiting illness, it is important to recognise the temporal and historical context of people's experiences.

While all illness disrupts the flow of time, none does so more than terminal illness. Heidegger (1962:40) argued that 'temporal determinateness' [*seine temporale Bestimmtheit*] permeates the process of interpretation. This study considers the past behaviours and future concerns that influence how participants make sense of their current experiences and asks: how do people interpret their place in their world, which has become irrevocably changed as a result of their life-limiting illness? How do they understand their Being-in-the-world, given that their life is limited?

Being-in-the-world that is 'ready-to-hand' and shows itself as 'present-at-hand'

Because we are 'in' the world, we are in relationship with other entities. This fosters a sense of familiarity where things are so close to us that we do not 'see' them; their meaning is 'present' yet in the background (Johnson 2000). Heidegger (1962) referred to this taken-for-granted way of being-in-the-world as 'ready-to-hand'.

Johnson (2000:137) coined the term "waking up to the world" to explain that when a hammer is broken or unavailable, we 'wake up' to the realisation that it is needed for a

specific purpose. The once implicit goal and purpose of the hammer come “into the foreground and we wake up to the world” (Johnson 2000:137):

When its unusability is thus discovered, equipment becomes conspicuous. This *conspicuousness* presents the ready-to-hand equipment as in a certain un-readiness-to-hand.

(Heidegger 1962:102-103. Italics in original)

When we become aware of what is broken or missing, this heightens our awareness of what we do have, and results in us missing even more what is not within reach. What we do have is seen in a new light, deficient in the shadow of what it could be if what is unavailable were to be present:

When we notice what is unready-to-hand, that which is ready-to-hand enters the mode of *obtrusiveness*. The more urgently we need what is missing, and the more authentically it is encountered in its un-readiness-to-hand, all the more obtrusive does that which is ready-to-hand become - so much so, indeed, that it seems to lose its character of readiness-to-hand. It reveals itself as something just present-at-hand and no more, which cannot be budged without the thing that is missing. The helpless way in which we stand before it is a deficient mode of concern, and as such it uncovers the Being-just-present-at-hand-and-no-more of something ready-to-hand.

(Heidegger 1962:103)

Therefore, it is only when something fails in its purpose (at times of breakdown) that it becomes conspicuous and the taken-for-granted meaning is exposed. Hermeneutic phenomenology thus enables researchers to uncover hidden or taken-for-granted meanings at times of ‘breakdown’ as experienced in illness.

The hermeneutic circle of understanding

For Heidegger (1962), understanding is a circular process that involves acknowledgement of our historicity in our search to understand the human experience (Maggs-Rapport 2001; Sembera 2007; Smythe et al 2008; Wrathall 2005). Heidegger (1962) believed that it is not possible to suspend our prior experiences or separate ourselves off from our values, beliefs or assumptions, arguing that we are historically produced.

'Background' is an essential component of the hermeneutic circle (Koch 1995). Our 'handed-down' background presents a way of understanding the world that cannot be made completely explicit (Koch 1995). Heidegger (1962) argued that we come to interpret and understand a phenomenon through our 'fore-structure' of understanding, which arises from our everyday involvement in the world.

This fore-structure is a threefold structure of understanding upon which all interpretation is based; it consists of fore-having, fore-sight and fore-conception (Heidegger 1962). 'Fore-having', from the German, *Vorhabe*, 'what we have in advance' or 'what we have before us' (Heidegger 1962) refers to my own familiarity with sexuality and intimacy that has made this interpretation possible. This arises from my own life experiences and relationships, including my role as a lecturer in sexuality. 'Fore-sight', from the German, *Vorsicht*, 'what we see in advance' (Heidegger 1962), refers to my individual perspective or point of view. 'Fore-conception', from the German, *Vorgriff*, 'what we grasp in advance' (Heidegger 1962), refers to my anticipated 'findings' (Heidegger 1962; Ironside 2005).

Heidegger (1962:176) explained, "the world which has already been disclosed beforehand permits what is within-the-world to be encountered". As a nurse, the experience of performing last offices¹⁸ the very first time as a student nurse informed the way I experience this procedure each subsequent time. At the same time, touching and handling a body after death is a unique experience each and every time. My experiences today are informed by layer after layer of prior experiences. I am now unable to fully imagine what it is like for a student nurse to experience this for the first time because I cannot undo all my prior experiences. I cannot 'bracket' them or set them aside.

Similarly, our first kiss informs and is embedded within our future experiences. Once we have experienced that first kiss, we can never experience a first kiss again. Each subsequent kiss is experienced in the light of this prior experience. Although the first kiss with a subsequent person is novel within that relationship, it is still experienced with the prior understandings gained from that first ever kiss. We cannot shed these experiences. Similarly, looking back, we cannot fully recall that first kiss because our subsequent experiences alter the lens through which we look back on these earlier experiences.

¹⁸ 'Last offices' is the process of laying out a body after death.

Even if someone else were to describe to me their first kiss, my interpretation of their experience would be from my perspective of being-in-the-world. “An interpretation is never a pre-suppositionless apprehending of something presented to us” (Heidegger 1962:191-192).

Gadamer (1976), a student of Heidegger, argued that ‘prejudice’ is not something negative that we should try to eliminate; it is through our pre-suppositions that we come to understand the world. Pre-suppositions are not necessarily distortions of truth (Koch 1996), as they “constitute the initial directedness of our whole ability to experience” (Gadamer 1976:9). Our pre-suppositions influence the process of interpretation, and our *a priori* world consists of cultural, historical and social contexts.

As our prior knowledge informs present and future interpretations and choices, one could say that our past is before us. This illustrates the hermeneutic circle of interpretation whereby understanding of the ‘whole’ requires reference to the individual ‘parts’, and understanding each ‘part’ requires reference to the ‘whole’. Schmidt (2006) used the example of words in a sentence to explain the hermeneutic circle of understanding. I struggled to understand the word ‘Dasein’ until I understood the sentence it was described in, and I have been unable to understand the sentence until I understood the word. Thus, it is by moving between the parts and the whole (between the description and the thing described) that understanding of both is enriched (Wrathall 2005).

Heidegger (1962) used a variety of examples to capture the complex relationship between an interpretation and the original. Greatrex-White (2008) exemplified this in her distinction between a climber’s view, a tourist’s view and an artist’s view of the same mountain. All are of the same mountain, yet different aspects of the nature of mountain are highlighted by these different perspectives; each person interprets the mountain based upon their own fore-structure of understanding, and so constructs a different version of it. Crotty (1996:45) explained, “there is no such thing as meaning that inheres in an object independently of any subject”. There is no such thing as one correct interpretation; it is just *an* interpretation.

For Heidegger (1962), thinking does not come to rest:

Each turn returns us to our starting point, but at a deeper level of ontological understanding, and each return opens the possibility of a new turn at a deeper level.

(Mulhall 2005:121)

Conclusion

The goal of interpretive phenomenology is to reveal shared understanding (Benner 1994; Gullickson 1993; Plager 1994). Heidegger's (1962) phenomenology is founded upon the ontological view that lived experience is an interpretive process that arises out of our being-in-the-world. Being and world are not seen as separate, but are co-constituted (Heidegger 1962).

All things are encountered through reference to our background understanding and every encounter is interpreted within this background, in its 'historicality' (Heidegger 1962). Therefore "the present may only be understood in terms of the past and the past in terms of the present" (Racher and Robinson 2002:473). This circularity of interpretation characterises Heidegger's (1962:363) concept of the 'hermeneutic circle' and describes the dialectic movement between the parts and the whole.

Although Heidegger did not explicitly develop a research methodology, it is possible to derive one from his philosophy (Johnson 2000) in which the philosophical underpinnings are embedded within the research process. In this study, the questions I have asked and the interpretations I reveal are informed by the philosophical lens of Heideggerian hermeneutics as I move towards an understanding of what it means to be human and experience sexuality and intimacy when living with a life-limiting illness.

I am called to consider how my fore-structures of understanding affect my interpretations of people's experiences. I have attempted to relax my pre-suppositions (Thompson 1990) by bringing them into awareness and stripping them "of their extreme character" (Gadamer 1976:152). I have endeavoured to hold 'loosely' my understanding of sexuality and intimacy as I know them and am reminded of being open to the possibility of what might be uncovered. The hermeneutic challenge in undertaking this study has been to reveal what was hidden by the taken-for-granted world of people's lives. In this thesis, I will endeavour

to show how sexuality and intimacy are experienced in-the-world, within the context of individuals' lived experiences.

Chapter 3: Method

Introduction

Mauthner and Doucet (2003:414) have criticised researchers who present their research methods as a set of procedures “in a social vacuum”, where the researcher is invisible. Because “we are integral to the social world we study” (Mauthner and Doucet 2003:416), and our “values and beliefs inescapably shape our work” (Miller 1997:155), our interpretations of experience are inevitably contextualised (Heidegger 1962). I have therefore made explicit my role as researcher within this methods chapter, and have explicated my rationale for each decision I took.

This chapter discusses the ethical issues that I considered in designing the study, and the value of involving individuals from affected communities in the planning stage. It then discusses how I recruited participants and collected and analysed the data. Both I, as researcher, and the people living with life-limiting illnesses have co-participated in the conversations that sought to interpret their experiences. For ease of reading, wherever I refer to ‘the participant’, this is in the conventional research sense, meaning the person whose experience I am trying to understand.

The challenges I faced and the lessons learned will be discussed later in Chapter 10.

Ethical considerations

Beauchamp and Childress (2001) set out four ethical principles: autonomy, nonmaleficence, justice and beneficence. The principle of justice requires due consideration of inclusion and exclusion criteria, by treating all fairly, and promoting good (beneficence) in research is a utilitarian concept of benefitting others (Boulton 2009). Autonomy, the principle of self-determination, is fundamental to research ethics (Addington-Hall 2002), and the principle of nonmaleficence establishes a moral duty to minimise harm to research participants (Holloway and Walker 2000).

Whether research participants in this study are considered a particularly vulnerable group is debatable. Some authors have categorised people who are terminally ill as vulnerable (de Raeve 1994; Liamputtong 2007; Raudonis 1992), while others perceive them to be

“disenfranchised” (Morse 2000:545) because of their exclusion from research. Addington-Hall (2007) argued that this population is not inherently vulnerable, and should not be afforded greater protection than other patients.

In contrast, Liamputtong (2007) advised against recruiting people who are terminally ill and in receipt of services because they might feel a need to ‘give something back’, and this could constitute coercion. This view perceives that gratitude for care could present as a compulsion to participate in research (Casarett and Karlawish 2000). However, this does not recognise that ‘giving something back’ might be an autonomous, altruistic choice.

An innovative Australian study sought the views of 22 hospice patients (aged 28-93) about participating in research (Terry et al 2006). These patients saw research as an opportunity to contribute for the benefit of others. As one participant explained:

It would be a way to give something back now before I die, I would have done something good for the future.

(Terry et al 2006:408)

Terry et al’s (2006) study found that patients were concerned that their autonomy would be compromised if the doctors and nurses caring for them did not invite them to participate in research, as this would be “being treated as already dead” (Terry et al 2006:412). It is therefore immoral to exclude people from research purely because they are terminally ill (Alexander 2010; Morse 2000), because this disempowering approach compromises autonomy by denying people a voice.

The ethical position I subscribe to is that research should be both necessary (Munhall 2007) and of value (Boulton 2009), and be of benefit to the population from which participants are drawn (Flaskerud and Winslow 1998). The benefits of research should outweigh any potential ‘harm’ to participants (Beauchamp and Childress 2001; Boulton 2009; Liamputtong 2007).

When considering ‘harm’, it has been important to consider the sensitivity of the research topic. Research is considered to be ‘sensitive’ if it:

Requires disclosure of behaviours or attitudes which would normally be kept private and personal, which might result in offence or lead to social censure or disapproval, and/or which might cause the respondent discomfort to express.

(Wellings et al 2000:256)

Because research on sexuality enters “private space” where “only ‘insiders’ participate” (de Laine 2000:67), it is particularly sensitive (Lee 1993; McCosker et al 2001). This is evident in the responses from people who gave their reasons for non-participation in this study¹⁹:

I don't wish to talk about or disclose intimate information outside of our family circle.

Female partner (aged 51-60)

I would be prepared to answer a written questionnaire, if that would help, but not to have an interview on such a private topic.

Female patient (age not given)

For these people, discussion of this sensitive subject was self-regulated and either not discussed at all, or restricted to very close relationships. It is interesting that these examples are from women. This does not suggest that men are more comfortable talking about sexuality (only six of these 18 non-participation reply slips where gender was stated were from men), but illustrates that, even with a female researcher, sexuality and intimacy can be too private to discuss.

Because of this intrusion into private areas of people's lives, ethical consideration was a high priority. It was important that I had the appropriate skills (Boulton 2009; McCosker et al 2001), anticipated the ethical issues in advance (Arendell 1997; Davies et al 1998; Dickson-Swift et al 2008) and took care of participants “before, during and after the interview” (Dyregrov 2004:398). Discussion of these issues will be incorporated throughout this chapter.

Involving affected communities in designing the study

So that people could choose whether or not to take part, it was important that they understood what was involved, as well as the potential consequences of the study

¹⁹ The invitation letter contained a reply slip for those who did not want to take part but were willing to give their reason.

(Liamputtong 2007). I prepared an invitation letter (Appendix 1) and an information sheet for patients (Appendix 2) and one for partners (Appendix 3) to explain the study's purpose and what was involved.

I was mindful of the risk of causing distress by using the term 'terminally ill' because terminology can be emotionally laden (Addington-Hall 2002). Aware that these words might not have been used in conversations with potential participants and their doctor, I opted for 'life-limiting illness' as a gentler description. In order to check out whether this terminology was appropriate, I consulted individuals with MND and cancer. They confirmed that, in order to avoid harm, it was important that those who were invited to take part were aware that they had a life-limiting condition.

These individuals also endorsed the value of the study, supported the inclusion and exclusion criteria (below), and made a number of useful suggestions for improving the information sheets (Appendix 4).

Gaining ethical approval

Because recruitment took place in different organisations, seeking ethical approval to conduct this study was a lengthy process. Approval was granted by Milton Keynes NHS Research Ethics Committee (NRES) (study number 08/H0603/3) (Appendix 6), Oxford Brookes University (Appendix 5), as well as from each of the three organisations involved in the study²⁰.

Throughout the study, three substantial amendments to the original ethics application were made in order to enhance recruitment. The first amendment (Appendix 7 approved in November 2008²¹) enabled recruiting staff to telephone patients to explain the study to them and offer to send further information by post. The second amendment (Appendix 8 approved in July 2009²²) extended the data collection period and enabled recruitment via hospice in-patient units. The third amendment (Appendix 9 approved in February 2010²³), emphasised the need to recruit younger patients in order to enhance maximum variation in

²⁰ This involved Research & Development (R&D) approval, as well as further ethical approval from one of the organisations.

²¹ Recorded by the ethics committee as amendment 2.

²² Recorded by the ethics committee as amendment 3.

²³ Recorded by the ethics committee as amendment 7.

the sample. This amendment also increased the maximum sample size in an attempt to recruit further partners of people with cancer²⁴.

Recruiting the story-tellers

In order to understand experience, we need to go to those who are living the experience (Todres and Holloway 2010). I was aware of the risks to myself in recruiting via advertisements, particularly on such a sensitive subject (McCosker et al 2001), so obtained permission from the senior consultants at three hospices and one MND clinic to recruit through their departments. Research has shown that hospice patients prefer to be invited to participate in research by a doctor or nurse who is involved in their care (Terry et al 2006). The consultants therefore suggested which members of staff I should approach to assist with recruitment.

In order to understand the meaning of sexuality and intimacy for people who were living with a life-limiting illness, it was important to interview both patients and partners of patients because partners' perspectives are often neglected in research (Esmail et al 2007; Gilbert et al 2010). Because the intention of phenomenological research is not to compare responses between participants, but to identify shared meanings (Thomas and Pollio 2002), it was not a requirement that both the patient and their partner from coupled relationships participate.

I considered the implications of compromising the principle of justice in my decision to exclude people who were unable to speak English (Sheldon and Sargeant 2007). However, I decided that the sensitivity of the subject matter precluded the use of an interpreter. My intention was to include a wide range of participants in terms of age, gender, relationship status²⁵, sexual identity and ethnicity, so adopted a purposive sampling strategy to achieve a maximum variation sample (Patton 2002). By recruiting this variety of participants, my intention has not been to draw comparisons, but to promote thinking (Smythe 2011).

²⁴ The rationale for this is discussed further under 'recruitment difficulties' in Chapter 10.

²⁵ Relationship status refers to whether people were single, in partnered relationships, married, divorced or widowed.

People were not eligible to take part if they were unable to consent or were considered to be too unwell by the recruiting professional to participate in the interviews. The inclusion/exclusion criteria specified that people had to be aware of the life-limiting nature of their illness:

Inclusion criteria

- Individuals with a life-limiting illness, or partners of a patient with a life-limiting illness
- Patients were aware that they had a life-limiting illness
- Patients were either single or in a relationship
- Individuals were heterosexual, homosexual, lesbian or bisexual
- Adults of all ages

Exclusion criteria

- Individuals who were considered by their consultant to be too unwell to participate in the interviews
- Individuals who would have been unable to give informed consent due to cognitive impairment
- Individuals who did not speak English (because the sensitive nature of the study precluded the use of an interpreter)
- Those under 18 years of age

Recruitment took place between August 2008 and October 2010, and was undertaken by a range of health and social care professionals (including doctors, specialist nurses and hospice support services). I met individually with these staff to explain the study and asked them to give an envelope containing the study details to a purposive sample of potential patient participants who met the inclusion/exclusion criteria. This envelope included the invitation letter (Appendix 1) and two information sheets (one for patients and one for partners ~ Appendices 2 and 3). The invitation letter invited the patient to take part in the research and, if they were in a partnered relationship, asked that they show the letter to their partner/spouse, giving them the information sheet for partners to read. Also enclosed were two reply slips (one for patients and one for partners of patients) and a stamped, addressed envelope.

Patients who are dependent on healthcare (Fine 2003) and those who are a 'captive audience' (Raudonis 1992) are vulnerable to coercion (Addington-Hall 2007; Addington-Hall 2002). Because people in receipt of palliative care services might not wish to disappoint the professionals that they have a close relationship with (Addington-Hall 2007; Bellamy et al 2011), I asked the staff recruiting to explain to prospective participants that staff would not be told by me whether or not they had decided to participate.

In order to enable prospective participants to make an autonomous, informed choice about whether or not to participate in the study, the information sheets explained who I was and the purpose of the study, and their freedom to participate or withdraw at any time. They explained that each person would be asked to participate in two interviews, one to two weeks apart. These interviews would be held in a mutually convenient place, and would last approximately one hour. If couples took part, they would be interviewed separately. The purpose of the second interview was to elaborate on the themes discussed in the first interview.

People who wished to take part were able to indicate this by returning the reply-slip or by contacting me directly (by email or telephone). This gave them time to consider the topic and their involvement in the study (Gabb 2010) and ensured they were not under any pressure to participate.

Who were the story-tellers for this study?

In total, 27 patients and 14 partners took part. There were 13 patients with MND (aged 46-82) and 14 patients with cancer (aged 43-81), 10 partners of people with MND (aged 32-76) and four partners of people with cancer (aged 44-69). Further demographic details are provided in Tables 1 and 2.

This is a significantly larger sample than is usual in phenomenological research (Creswell 1998; Todres and Holloway 2010; van Manen 1990), as thematic coherence can be achieved with as few as three or four participants (Thomas and Pollio 2002). However, this study needed a larger sample for a variety of reasons. Larger numbers do not indicate a greater importance of sexuality in people's lives, but my 'findings' are more likely to be influential in clinical practice, where there can be a tendency for the quality of research to be judged by sample size. Attrition rates can be high in this population (Addington-Hall

2002); four patients²⁶ and two of their partners²⁷ did not proceed to the second interview because they were less well. One further patient did not respond to the email to arrange follow-up. Larger numbers were also necessary because many people had difficulty verbalising their experiences on this otherwise unspoken subject, and others who were very unwell were able to provide limited data.

The sample consisted of 19 men (13 patients and six partners) and 22 women (14 patients and eight partners). However, it lacked diversity in terms of ethnicity, as all but one participant was 'white British'. All participants defined themselves as heterosexual, except one lesbian woman and one bisexual man. Two of the partners still chose to participate even though they were bereaved at the time of the first interview.

Although proxy interviewing can be useful for those with speech impairments, or when speech is likely to tire individuals (Wenger 2002), this was not appropriate for this study because individuals would only be able to provide their view of their coupled relationship and would not be able to speak on behalf of their partner. Barriers to communication can be overcome to enable people with limited communication an opportunity to participate (Morse 2000), and some participants used alternative means of communicating (such as an alphabet board and an electronic speech-assistive device).

²⁶ Three people had cancer, and one had MND.

²⁷ One person's partner had cancer and the other's partner had MND.

Table 2: Demographic details of the ‘patients’ who participated

Pseudonym	Age	Relationship status	Diagnosis	Interviewed during the last year of life?
Susie	43	Married	Bowel cancer	Died 7.5 months later
Maria	44	Divorced	Brain tumour	
Jane	44	Partnered ²⁸	Pelvic cancer	
Kim	46	Single	MND	
Maureen	47	Married	Breast cancer	
Angela	47	Married	Breast cancer	
Simon	50	Partnered	MND	
Greg	51	Partnered	MND	
Tom	52	Married	MND	
Nancy	56	Married	MND	
Sharon	56	Married	Uterine cancer	
Ivor	56	Single	Penile cancer	Died 10 days later
Richard	58	Separated	MND	
Clive	59	Married	MND	
Pete	63	Divorced	MND	
Rita	64	Married	MND	
Kathleen	64	Married	Pancreatic cancer	Died 15 days later
Julie	68	Married	MND	Died 11 months later
James	70	Married	MND	
Les	70	Married	Prostate cancer	Died 8 weeks later
Dora	71	Divorced	Renal cancer	
Cheryl	74	Married	MND	Died 7 months later
Arthur	74	Married	Bowel cancer	Died 1 year later
Bert	75	Married	Prostate cancer	
Stanley	78	Married	Bowel cancer	
Grace	81	Divorced	Bowel cancer	
Jim	82	Married	MND	Died 2.5 weeks later

²⁸ A partnered relationship indicates those who live with or apart from their partner.

Table 3: Demographic details of the ‘partners’ who participated

Pseudonym	Age	Marital status	Patient’s diagnosis	Interviewed during the last year of the patient’s life?
Michelle	32	Widowed	MND	Bereaved for 3 months
Sean	36	Partnered	Cancer	
Katy	44	Married	Cancer	Bereaved 2 weeks later
Claire	45	Partnered	MND	
Stuart	55	Married	MND	
Frances	55	Married	Cancer	Bereaved 2 months later
Sally	56	Partnered	MND	
Nick	59	Married	MND	Bereaved 11 months later
Michael	65	Married	MND	
Stella	66	Married	MND	
Betty	69	Married	MND	Bereaved 2.5 weeks later
Jacky	69	Married	Cancer	
Barry	75	Married	MND	Bereaved 7 months later
Gilbert	76	Widowed	MND	Bereaved for 2.5 months

Gathering the stories in conversation

I needed to make a number of decisions regarding how to gather the stories. The first of which was whether to conduct one-to-one or conjoint interviews.

One-to-one or conjoint interviews?

Conjoint interviews can be useful in providing insight into the couple’s experience (Taylor and de Vocht 2011) of diseases such as cancer (Morris 2001), or a shared experience such as infertility (Sandelowski 1993). The presence of a partner in a research interview can be beneficial in facilitating corroboration, supplementation, probing and challenge (Allan 1980; Padula 1996; Racher 2003). However, joint interviews can be problematic if one party discloses issues that their partner had not anticipated (Larossa et al 1981) or if partners disagree (Davies et al 1998).

The aim of this study was to understand the experiences of patients and partners of patients. In my experience of nursing people facing end of life, I have found that even those who describe a very close relationship often have thoughts, feelings and beliefs that they choose not to share with their partner. If they do discuss them with their partner present, they might modify their language or the emphasis given. Therefore, although individuals might be prompted by their partner to elaborate further or reveal additional experiences, their partner's presence in a research interview might also inhibit the expression of thoughts, feelings and experiences (Taylor and de Vocht 2011). This does not suggest that they necessarily have secrets to hide, but that they might wish to protect their partner and so avoid referring to emotive incidents. I therefore decided to interview patients and partners separately.

This decision is consistent with Heideggerian philosophy because it is recognised that experiences are co-constructed (Heidegger 1962; Racher and Robinson 2002). In joint interviews, couples would "co-construct their shared understanding of their world" (Taylor and de Vocht 2011:1581). In interviewing couples separately, I would not eliminate the pull of 'the they', for Dasein is always in relation with others (Heidegger 1962) and their partner might be "conspicuous by their absence" (Taylor and de Vocht 2011:1579). However, individuals would be more able to 'choose to choose' and present their own perspective without concern for their partner's reaction:

A resolute, authentic Dasein chooses to choose rather than let itself drift along and be chosen by the anonymous pressures of *das Man*.

(Cerborne 2006:64. Italics in original)

One-to-one interviewing therefore provided opportunities to elicit individual experiences, as well as individual perceptions of shared experiences (Taylor and de Vocht 2011).

Establishing and building relationships

Rapport and trust are crucial in effective interviewing (Carolan 2003; Lee 1993; Murray 2003; Pleschberger et al 2011). My credibility as a researcher is likely to have been influenced by the introduction that the recruiting professionals gave, as I might have seemed less of a 'stranger' (Lee 1993). The validation of the study by the patients' consultants also gave value to the study.

Research has shown that hospice patients have been unwilling to speak of their experiences with someone who was unfamiliar with the issues (Terry et al 2006). One individual explained:

They would have to be in it with you, not someone who doesn't have a clue about dying.

(Terry et al 2006:409)

I explained in the information sheet that I teach sexuality, and that I work as a palliative care nurse (in a named hospice). This explanation was intended to validate my interest in the subject, and my credibility as someone familiar with people's experiences of illness and dying.

The relationship between researcher and participants is of vital importance in sensitive research (Gabb 2010; Pleschberger et al 2011), and the interviews were shaped by prior interactions between me and the participants (Mishler 1986), by our shared historicity. It was important to create an atmosphere in which participants felt comfortable to share their experiences (Dickson-Swift et al 2008; Liamputtong 2007). When people returned the reply slip indicating their willingness to take part, I telephoned to arrange the first interview. Even though I had explained who I was and the purpose of the study in the information sheets (Appendices 2 and 3), I was conscious of the importance of this telephone call as people would gain some sense of me as a person. My words and tone of voice, I hoped, conveyed warmth, respect and empathy as I checked if they had any questions and arranged a convenient time and location for the interview. I left people with my mobile number in case they needed to rearrange the interview or if they had any further questions.

Developing this relationship prior to the interview proved more challenging with participants who were unable to speak²⁹, and when arranging interviews with couples who had returned their reply slip in the same envelope. The person answering the telephone tended to presume that they were speaking on behalf of the other, even when I asked if their partner had anything they would like to ask me. In these situations, I was reliant upon establishing relationships after we had met.

²⁹ These interviews were arranged by email.

It was important that the interviews were in a non-threatening environment (Gabb 2010) in which participants felt most comfortable (Liamputtong 2007). Most people chose for the interviews to take place in their own homes, though two men wanted the interviews to take place in their workplace, which might have afforded them greater privacy³⁰. Three people were interviewed in a hospice: one of these was an in-patient, one partner was visiting her husband, and the third preferred this setting because his partner did not want to take part in the study and he was concerned that she would prevent his participation³¹. One patient asked for the second interview to take place when receiving respite care away from home.

When people chose their own homes for the setting, I reminded couples that they would be interviewed separately and checked with them on the telephone if we would be able to speak in private. When the interviews were conducted in another setting, I put a notice on the door saying, 'Meeting in progress. Please do not disturb'.

Some have suggested that researcher self-disclosure is appropriate (Dickson-Swift et al 2007) and even desirable (Lee 1993). However, given the topic, I did not feel it appropriate to disclose any detail about my own relationships except to confirm, when asked, that I was married and had a son. Some participants asked my son's age and his plans for the future, and I felt it was important that I demonstrated ease at answering these questions. This reciprocal disclosure, albeit very limited on my part, was important for establishing rapport.

Clarke (2003) found that providing information and practical help to study participants enhanced rapport. There seems to be a fine line between acting empathically in responding to requests for help with daily tasks, and doing these as a means of furthering rapport. When I was asked to help someone with a drink, to reach something from a high shelf, or pick up the post, I did this willingly, without consideration that it might in some way benefit me or my study.

³⁰ Neither of these men's partners took part in the study, and I was unclear whether or not they had told their partner of their involvement.

³¹ It was not my intention to invite people to participate more than once because this could be coercive. However, when two different professionals had inadvertently mentioned the study to this patient, he was very pleased to have the information because his partner had thrown the first invitation letter away. He said: "this is important to me. She can't stop me now".

Establishing consent

In order to be able to make an informed choice, individuals needed sufficient information about the purpose and nature of the study (Elam and Fenton 2003). This was provided in the written information. Before the first interview began, I gave people an opportunity to ask any further questions and then obtained their written consent (Appendix 10).

Individuals were informed of their right to withdraw, without giving a reason and without their care being affected.

Two participants were physically unable to sign the consent form. Therefore, their partners (who had enduring power of attorney) signed the form on their behalf. I was satisfied from the conversations we had that the patients did understand their rights and what was involved.

Maintaining the safety of the storytellers

The wellbeing of participants took precedence over the research aims at all times. Before each interview began, I reminded participants that they could stop at any time (temporarily or permanently), without giving a reason³². I verbally re-established consent before the second interview because of the likely deterioration in the patients' condition over time (Addington-Hall 2005), and the potential for deterioration in their cognitive function, rendering their prior consent invalid (Lawton 2001).

People only reveal more private aspects of their lives when they feel safe to do so (Lee 1993). Research on death and dying can be emotive (Dickson-Swift et al 2008), and I was mindful that participants might raise issues they would rather avoid (Addington-Hall 2002). However, not everyone finds it distressing to talk about emotive issues (Ryan et al 2009), and crying is not necessarily a negative experience, because people value the opportunity to express emotions (Cook and Bosley 1995) if the researcher is "comfortable and willing to listen" (Chapple 2006:54).

As researchers, it is impossible to predict whether a topic or question will trigger an emotional reaction for a participant (Elam and Fenton 2003). I was also mindful that it is difficult "to avoid a question which suddenly touches on a sensitive subject from a pleasant interviewer who is sitting on your sofa" (Sheldon and Sargeant 2007:165). Because of this,

³² This had already been explained in the information sheet.

I reminded people at the beginning of each interview of their right not to answer any question.

I needed to ensure that the interviews did not *cause* distress, but were “a medium through which participants expressed their distress” (Lowe and Gill 2006:593). Some researchers have recommended that interviews be terminated if participants become distressed (Pleschberger et al 2011). However, my approach was to not decide this on participants’ behalf, but to give people the opportunity to stop if they wanted to (Morse 2002). Using ‘process consent’ (Munhall 1988), I re-established their willingness to continue (Munhall 2007; Sheldon and Sargeant 2007) whenever they appeared tired, unwell or distressed. Only one participant chose to terminate the interview³³.

Throughout the interviews, it was important that I retained a focus upon, not only the research question, but also the physical and emotional well-being of participants (Arendell 1997). I was mindful that the conversations might provoke emotional reactions (Liamputtong 2007; McCosker et al 2001) and that patients nearing end of life tire easily (Morgan 2010; Radbruch et al 2008), which might affect concentration (Addington-Hall 2007). In order to protect participants from an unnecessary burden of excessive tiredness (Addington-Hall 2002), I was careful to use the time appropriately and therefore gently brought the conversation back to the topic if participants ventured off onto other topics.

All participants were given the opportunity to debrief at the end of each interview (Alty and Rodham 1998). However, I was aware that issues might arise in the interviews that could need further processing, and that my role was that of researcher, rather than nurse (Murray 2003). I was mindful that talking about their experiences might evoke painful and traumatic memories (Kvale 1996), and therefore created a leaflet (Appendix 11) itemising a range of local and national sources of information and support (permission to this effect was granted from the local agencies³⁴). The potential benefit of this leaflet was endorsed by individuals from affected communities (Appendix 12).

It was a recommendation of the research ethics committee that patients’ General Practitioner (GP) be informed of their participation in research. This was optional, and I

³³ This occurred at the end of the interview when I’d asked Dora if there was anything else she wanted to tell me. She began recalling a dream which distressed her, and then chose not to say anymore.

³⁴ Names of individuals and organisations have been removed to maintain anonymity.

only sent a letter to inform their GP if patients gave explicit permission on their consent form.

I wrote to the participants who had provided an address within three to five days of the second interview, thanking them for their participation and for sharing their experiences. I also provided them with a further opportunity to contact me if they had any remaining questions or comments in relation to their involvement in the study. Nobody contacted me following this letter.

How the stories were gathered

Once consent was established, I began with 'non-threatening' topics by asking people for demographic information (Ryan et al 2009). This included age, gender, partner's age and gender (if in a relationship), ethnicity, diagnosis and time since diagnosis.

In order to demonstrate my acceptability of diversity and to facilitate disclosure, even if I knew that someone was married, I phrased a question to determine sexual identity:

Not everyone who is married describes themselves as heterosexual. Some people describe themselves as bisexual or gay. How would you describe yourself?

Because diagnosis is also a sensitive issue, I was careful not to use words such as 'cancer' unless the participant had already done so.

It is conventional in phenomenological research to use unstructured interviews, where the participant is asked to talk at length about the phenomenon being studied, with the researcher adopting a listening role (Cohen et al 2000; Moustakas 1994; Todres and Holloway 2010; Wimpenny and Gass 2000). Semi-structured interviews are not recommended because they constrain the interview and subsequent data generated (Koch 1996; van Manen 1990; Wimpenny and Gass 2000). A single opening question is recommended, with no further guidance from the researcher (Polit and Beck 2004; Wood 1991) except probing until the experience has been fully described (Ray 1994). The rationale for this approach is to enable issues that are important or meaningful to participants to emerge within the data (Sweeney et al 2007), because the understanding and meaning that people have of their world is embedded in the stories that they tell (Kahn 2000).

However, it is extremely difficult to conduct a completely unstructured interview because they inevitably focus upon an area of the researcher's interest (Pontin 2000; Rose 1994a).

Every inquiry is a seeking [*Suchen*]. Every seeking gets guided beforehand by what is sought.

(Heidegger 1962:24)

At every step, the researcher chooses which comments from participants to probe and which not to probe. A research interview is a social interaction (Ryan et al 2009) but is also an unequal relationship (Kvale 1996), a conversation with a purpose that is chosen by the researcher (Taylor 2010a).

Given the personal and sensitive nature of sexuality, I anticipated that there would be problems with the 'standard' opening question, 'tell me about your experiences of...' I found that most participants were not at ease speaking at length about the subject, and required much more input from me. I asked participants:

- Their reason for taking part in the study
- How their illness/condition (or their partner's illness/condition) affected them in their day-to-day life
- Whether this had affected intimacy or sexuality in any way
- If healthcare professionals had spoken with them about these matters
- If there was anything else they wished to add

The sequencing of these topics was not restrictive, but enabled the conversation to move from less sensitive to more sensitive questions (Elam and Fenton 2003) and, in so doing, facilitated rapport (Elam and Fenton 2003; Gabb 2010; Kinsey et al 1948; Rose 1994a).

Understanding how illness affected people (both patients and partners) in their day-to-day life provided valuable contextual information, as well as examples that I could refer back to in the context of sexuality and intimacy. It also enabled participants to talk at length and begin to relax before I progressed onto more sensitive questions (Ryan et al 2009).

Because I used a framework, Rose (1994a) would suggest that I imposed a structure. However, the interviews were not constrained by this framework, as flexibility was important, with me following the leads of participants (Coombes et al 2009; Koch 1996; Ryan et al 2009) and enabling topics to be discussed that I had not anticipated. I

spontaneously used a variety of probes to elicit further information (Cohen et al 2000; Polit and Hungler 1991) or detail (Benner 1994), and to seek clarification (Jasper 1994; Ryan et al 2009). Examples included:

- Can you tell me more about that?
- Are you able to give me an example?
- You spoke of converting the dining room into a bedroom; will you be making it a double bedroom?
- Sometimes people with bulbar onset MND have more difficulty controlling saliva, is this something that you have experienced?
- How do you manage that?
- What is that like for you?

Although I followed the leads given by participants, I also guided the conversation by returning to topics previously mentioned and by asking questions about some topics not already described. Sometimes, therefore, it was I that led and participants that followed when I brought the conversation back to sexuality and intimacy:

The interviewer and interviewee set off on a journey. As each speaks, they make a choice between whether to stay on the same path, to retrace their steps, or whether to wander down a different path.

(Taylor 2010a)

My aim was to enable participants to take the lead on this conversational journey, and silence was invaluable (Kvale 1996) in giving people time to reflect and make sense of their experiences (French 1983; McCleod 2007). However, I also found that I needed to be much more direct and precise when asking about people's sexual experiences (Laumann et al 1994). As Kinsey et al (1948:60) explained, participants are:

Hesitant to discuss things which seem to be both outside of the experience of the interviewer and beyond his knowledge.

By 'naming' aspects of sexual expression, I indicated my acceptance of the subject. For example, none of the participants volunteered information about masturbation until I had explicitly referred to it myself. In many of the interviews I asked:

I don't know if you feel able to say, but have you ever, or do you practice masturbation?

It was not a conscious decision to ask in this way, but the 'warning shot' is one that I use as a palliative care nurse before asking particularly sensitive questions, and I instinctively adopted the same style in the interviews, giving people the option not to talk about this aspect of their lives if they did not wish to. Interestingly, I did not need to follow this closed question with a more open one, 'can you tell me more about that?', as participants tended to elaborate once I had introduced the subject and given them permission to speak the unspeakable by showing my acceptance of it.

The interviews therefore tended to resemble conversations, in that they contained very little pre-determined structure and information was exchanged in both directions (Cohen et al 2000). This two-way exchange is consistent with Heidegger's (1962) view that we make sense of our experiences *within* them (as opposed to detached from them). Both I and the participants were making sense of experiences 'in the world' as they were discussed. I have therefore chosen to describe the interviews as 'conversational' because a conversation is not led or conducted, it flows and "has a spirit of its own" (Gadamer 1982:345); conversations enter unknown territory because "no-one knows what will come out in a conversation" (Gadamer 1982:345).

I was mindful that time was limited for both the patient and partner participants, and decided that two interviews would be sufficient to gather useful data, and that more, as recommended by Clarke (2003) and (Kahn 2000), would take up too much of people's time.

I had anticipated that people might not have spoken about many of their experiences before, so the second interview provided opportunities to capture any thoughts or additional information once people had reflected on the first interview (Clarke 2003). This second interview was not, contrary to the views of others, necessary for building rapport (Clarke 2003; Lee 1993) and many participants described feeling unsure if they had anything to add at the second interview, believing they had fully described their experiences (Thomas and Pollio 2002). However, the advantage of the second interview was that it provided opportunities to pick up on points in more detail, without tiring people unnecessarily in the first interview. People elaborated on their previous description, resulting in, at times, richer data.

Because the health of the patients could rapidly change, I tried to arrange the first interview within one week of receiving the reply slip, and to arrange the second interview one to two weeks later. The interviews averaged 66 minutes in length and, with the consent of participants, were audio-recorded.

Each interview was transcribed verbatim by one of two transcribers. A confidentiality agreement was prepared for the transcribers so that they also agreed to protect the identity of participants and delete all audio-files and transcripts once the transcripts had been returned to me. To maintain anonymity, all names within the transcripts were replaced with pseudonyms. The data have also been de-personalised and identifying details changed to try and avoid deductive disclosure in publications or presentations (Lee 1993). To protect anonymity, the type of cancer has also not been named if it is unusual.³⁵

My own position as gatherer of stories

Being-in-the-world is always in relation to other people. Being-with-others [*Mitsein*] is a mode of Dasein's being (Heidegger 1962), and individuals co-construct meanings within the world of others (Conroy 2003). Because research interviews create a new way of being-in-the-world-with-others, it was important that I consider my own position in gathering people's stories, and the influence that I might have upon the participants and the stories they shared.

Interview relationships are both complex and dynamic (Arendell 1997). They occur in a gendered context (Arendell 1997; Williams and Heikes 1993), with the personhood and characteristics of the researcher influencing what people share (Clarke 2003; Radley and Billig 1996; Wenger 2002). Given the subject matter, I was particularly aware that my gender might be of particular significance for some people, enabling or restricting their disclosure. Interestingly, Johnson and Delamater (1976) found that gender resulted in very little variation in responses to a survey on sexual behaviour, the researcher's level of ease with the subject being more of an issue than gender. However, they found that women did report being more comfortable when interviewed by a woman.

³⁵ The exception here is the participant with penile cancer, who gave explicit permission for his relatively rare condition to be named. This man recognised that the healthcare professionals who had cared for him might recognise him within this thesis, or any publications, and volunteered permission for his name to be used.

However, gender is “not an insurmountable barrier to establishing rapport” (Williams and Heikes 1993:289), and whether interviewing men or women, my gender will have played a part in either enabling or limiting disclosure. In view of this, it was important that people knew in advance that it would be a woman conducting the interviews, and I was glad that my first name is gender-specific.

Kinsey et al (1948) recommended that the researcher forms no judgement and “offers no objection to any type of sexual behaviour in which the subject could possibly have been involved” (Kinsey et al 1948:41). They advocated that researchers “listen without adverse reaction” (Kinsey et al 1948:41), but avoid “cold objectivity” (Kinsey et al 1948:42) as this is unlikely to achieve the rapport needed for frank and honest disclosure of sexual behaviour.

Similarly, Masters and Johnson (1970:28) recommended that, when gathering people’s experiences, we should be free from “sexual prejudice” and:

Convey an aura of comfort with the subject (and respond without embarrassment to unfamiliar material)... create an atmosphere free of discernible prejudice toward the sexual values, ideas or practices discussed.

As explained in Chapter 2, I cannot be free from any bias or pre-suppositions (Heidegger 1962) because who I am and my prior experiences influence interactions and mine and others’ interpretations thereof. I considered it important that I portray an open-ness and acceptance of whatever participants shared with me. I needed to be open-minded (Rose 1994a) and not show any surprise or censor any disclosure (Lee 1993). My breadth of experience with both sexuality and nursing people who were dying enabled this.

I was able to demonstrate my ease with the subject in the interviews. For example, none of the participants mentioned using sexual aids unless invited to do so. Once I had named them, however, many participants seemed very keen to share their experiences. Such topics would, it seems, have remained taboo unless I had demonstrated my comfort in discussing them, and, therefore, my acceptability of what might otherwise be considered deviant. By asking about them, I hoped to “create an atmosphere free from discernible prejudice” (Masters and Johnson 1970:28), demonstrating that I would not be disapproving of these activities.

Using a reflective journal throughout the study

As explained in the previous chapter, it is not only participants who bring their experiences to the research encounter (Drew 1989; Koch 1996; Smythe et al 2008); as a researcher, my own pre-suppositions cannot be suspended (Koch 1996:178).

Because I co-constitute the 'findings' along with the participants, my own fore-structure of understanding needed to be "examined and explicated" (Draucker 1999:361). Once I had decided on my research question, I asked another student to interview me so that I could record my own thoughts, feelings and experiences about the topic. Throughout data collection and analysis, I used a reflective journal to record my ideas, impressions, feelings and any conflicts generated (Murray 2003; Smith 1999). Through journaling, I have been able to question my motives, actions and thinking, and, in so doing, am more able to demonstrate the trustworthiness of this research (Koch 1994).

I have included extracts from my journal within this thesis to illustrate my thoughts and feelings during data collection, so that the reader might more readily see how my views and values have influenced my interpretations, to see the lens through which I view the world. It is the fusion of this lens with that of participants that generates the 'findings' presented in the following chapters.

Working with the stories

When the transcripts were returned to me, I systematically checked them by listening to the recordings several times to ensure they were an accurate presentation of what was said, as tone of voice and inflections can convey different meanings (Mishler 1986). I found it important to be able to hear the tone and cadence in people's voices as they spoke of their experiences. Hearing the silence seemed to transport me back to the setting where the interview took place, and I was able to 'see' their expressions (their comfort and discomfort) as they spoke. However, I had not travelled back in time. I was no longer *in* conversation; I was able to concentrate on what was being said in a different way, revealing new perspectives (Chesney 2000).

Some researchers have advocated returning to participants to review the transcripts (Morse et al 2002), and Chapple (2006) suggested that people who are terminally ill might need assistance from a friend or relative to do this. Even though Liamputtong (2007) has

proposed that returning transcripts to participants shows respect for their contribution, I chose not to return transcripts to participants for moral and methodological reasons.

Firstly, member-checking is not justified (McConnell-Henry et al 2011; Morse et al 2002; Ricouer 1981) because stories are re-shaped in their re-telling (Frank 1997) and the original meaning of participants cannot be reproduced. Indeed, “interpretations are never-ending” (Taylor and de Vocht 2011:1579). When the spoken words of participants are ‘fixed’ in written transcripts, they “take on a life of their own” (Smith 1999:362). Therefore, if participants had read the transcriptions after the interview, they would have been reading them in a different context to when their words were originally spoken, and their reading would have produced new interpretations of meaning (Allen 1995).

Diekelmann and Ironside (2006) suggested that it can be useful if researchers return to participants to confirm the emerging understandings. However, given the nature of the ‘patient’ participants’ declining health, many of them would not have been alive or well enough when analysis was complete. Likewise, many ‘partner’ participants would have been likely to be bereaved (and possibly in a new relationship). It was likely, therefore, that participants’ perspectives on sexuality and intimacy would have altered since the data were collected. This would result in them interpreting their prior words from a new position (Allen 1995; Taylor and de Vocht 2011).

I was also concerned about compromising confidentiality. It was likely that the patients who had participated would be less well or might have died in the intervening time. The patient might not have told their partner or other family members of their involvement, and I was concerned that a family member might open their post. I therefore considered it showed greater respect not to return the transcripts.

To analyse the data, I used an adaptation of Diekelmann’s (1992) 7-stage hermeneutic process in order to uncover shared meanings because it encapsulates the cyclical process that is fundamental to Heidegger’s (1962) hermeneutic circle of interpretation. Analysis is a series of steps (Smythe et al 2008), and is not linear, as might be inferred from its description, but is an iterative process (Morse et al 2002), going back and forth between the transcripts and the literature (Diekelmann and Ironside 2006). As one Heideggerian hermeneutic phenomenologist described it:

There is lots of backwards and forwards reflexivity between thinking and writing and reading, but it is also between one interview and all of the interviews. The thinking goes in quite a lot of different directions.

(Deb Spence in Smythe et al 2008:1394-1395)

I adapted Diekelmann's (1992) 7-stage process (Figure 1) because it assumes that the researcher will be working with others in a team. My role as a PhD student was to identify the emerging themes and constitutive pattern, and this was not a responsibility shared with my supervisors. They were able to question, challenge and confirm my interpretations as they evolved, but the responsibility for identifying themes and patterns was mine alone. It is worth noting that, even if I had been working as part of a team, others will have imposed their own interpretations upon the text, for their own "conceptual leanings" and "interpretive background" will have influenced their interpretations (Koch 1995:834).

Using a "parts-to-whole process" (Thomas and Pollio 2002:35), I moved backwards and forwards between the interviews to see if other narratives supported or refuted the emerging themes (Andrews et al 1996) (Figure 2). I listened to the insights that emerged, mindful not to reject them even when they were unsettling (Smythe et al 2008). This circular process of understanding, moving between the parts and the whole, has been described by Conroy (2003) as a spiral and by Sloan (2002) as helical. These visual representations reflect the fluidity of our interpretations that are described by the Maori writer, Piri Sciascia (1995:15):

The taura [pattern, or model] of the old provides the basis of formation for the new.

Figure 1: The 7-stage hermeneutic process for analysis

Stage 1 I listened to each recorded interview and read through the transcribed text in its entirety in order to gain a general understanding of the experiences of each individual living with their life-limiting illness. Writing a summary of the interviews assisted this process.

Stage 2 Using NVIVO software to manage the data, I identified emerging themes within each transcript that reflected meanings in the text.

Stage 3 In meetings with my supervisors, they questioned, affirmed and challenged these interpretations. I returned to re-read the original transcripts and listened again to the interviews when further clarification was needed.

Stage 4 I re-read all of the transcripts to identify common themes, and began to explore these themes through writing, using excerpts from the text, exemplars and paradigm cases³⁶.

Stage 5 I identified a 'constitutive pattern' (the highest level of hermeneutic understanding). This pattern describes the relationship among the themes across all the transcripts.

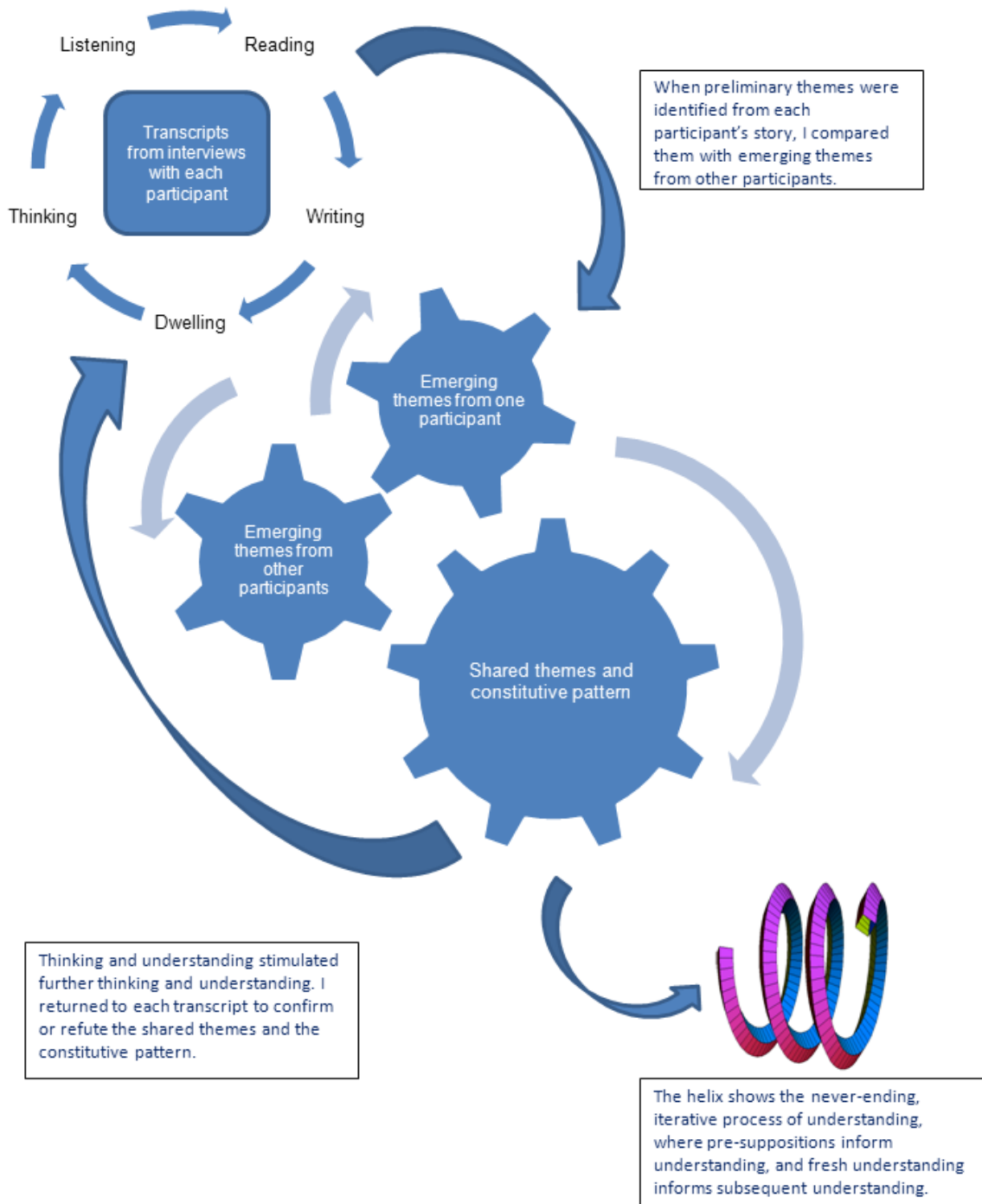
Stage 6 I compared the transcripts, looking for similar or contradictory interpretations of the emerging themes and constitutive pattern. I discussed these common themes and pattern in a variety of forums to challenge and further develop my interpretations.

Stage 7 I returned to the philosophical and theoretical literature to further refine my interpretations within a broader context.

(Adapted from Diekelmann 1992)

³⁶ A paradigm case is an account that is offered by one participant that is a particularly strong instance of a theme that is present in multiple texts (Benner 1994).

Figure 2: The iterative process of hermeneutic understanding



Throughout data analysis, I asked myself, why is s/he telling me this? What is s/he trying to say? What is it like for them? What does it mean? As I glimpsed fresh insights and refuted previous ones, my pre-suppositions evolved and changed on my spiralling journey closer towards understanding. Each time that I returned to re-read the transcripts, I returned with different perspectives:

The hermeneutical ripple effect of the spiral is dynamic, impinges on others interpretations, and, over time, changes the understandings of all.

(Conroy 2003:43)

From the emerging themes, I identified a constitutive pattern, which is the highest level of analysis (Diekelmann 1992; Diekelmann and Ironside 2006). Some of these themes are shown in Figure 3. The constitutive pattern I identified “connect[s] and weave[s] together” the themes (Smith 1999:362); it is portrayed (in Figure 4) diagrammatically, showing the inter-relationship between themes (Thomas and Pollio 2002).

My ‘findings’ are interpretations; they are not the presentation of one ‘correct’ understanding or ‘truth’ (Smythe 2011), for with every revealing, there is also concealing (Heidegger 1962). My interpretations are therefore “a calling, an invitation to others to come and look and think” (Smythe et al 2008:1393); to join me as I journey ‘on the way’ to understanding (Diekelmann 2005).

Figure 3: Interview extracts illustrating some emerging themes and the constitutive pattern

Extract from 1st interview with Tom

BT I wonder if you could tell me about your experiences in relation to sexuality.

Tom Right. Um, well I need to be very upfront and say that it's been a fairly one-sided relationship with my wife for quite a long time now. Um, complications around birth of the children and corrective surgery and things like that has made it less enjoyable for my wife over the years. And on many occasions our sexual relationship has been very much probably to keep me happy more than for her pleasure ... I find it difficult to get her to relax and do what she wants to do and what she wants to enjoy ... like bringing her to orgasm or something like that, would be something that I know that she enjoys, and she gets a lot of pleasure out of it, but she won't allow me to do it, and there's a barrier there and I don't know what that barrier is. We have had discussions about it, we even actually consulted [a therapist for] a number of years about it but we didn't get anywhere 'cause again it was just something she didn't want to talk about. And I just felt it was something that we couldn't take forward unless both of us were for it, um, but funny enough when the diagnosis came through in February, probably that's been our most, um, intensive period of sex for, we went through about a week where we were just together all the time and it was just really strange and then it just completely disappeared again and I don't know why that is. Maybe it was just the emotion of the news straight away, um, but, um, but I mean recently there's probably been a period of two or three months and I mean we went between, um, having sexual intercourse because you just, well, it just didn't work out. And the last time was probably, again it was just very much for my benefit, totally for my benefit so it was um, it was very quick and (laughs), it's a bit false really if you know what I mean.

In this extract, Tom described 'sexuality and intimacy as disconnecting'. This reveals itself as:

- Disconnecting as a legacy from the past (pre-existing sexual difficulties impeding connecting)
- Disconnecting as rejection
- Disconnecting as lack of reciprocity
- Disconnecting as rights and duties.

For Tom, sexuality and intimacy were also experienced as 're-connecting in the shadow of impending death' (during what he described as that "intense period of sex").

Extract from 2nd interview with Tom

Tom I am worried that, I'm trying to put it to the back of my mind a lot more now, but it does worry me that that side of our relationship [sex] will be the first thing in my life that will just go and never happen again

BT How does that leave you feeling?

Tom Um, disconsolate, not depressed, just disconsolate. Is it that important? I don't know. How do you weigh these things up, you know, when you're not well and you know things are not going to improve necessarily? Is that the most important thing in your life? Um, there's a part of me that actually says it's probably more important now than it's ever been

BT Can you say a bit more about that?

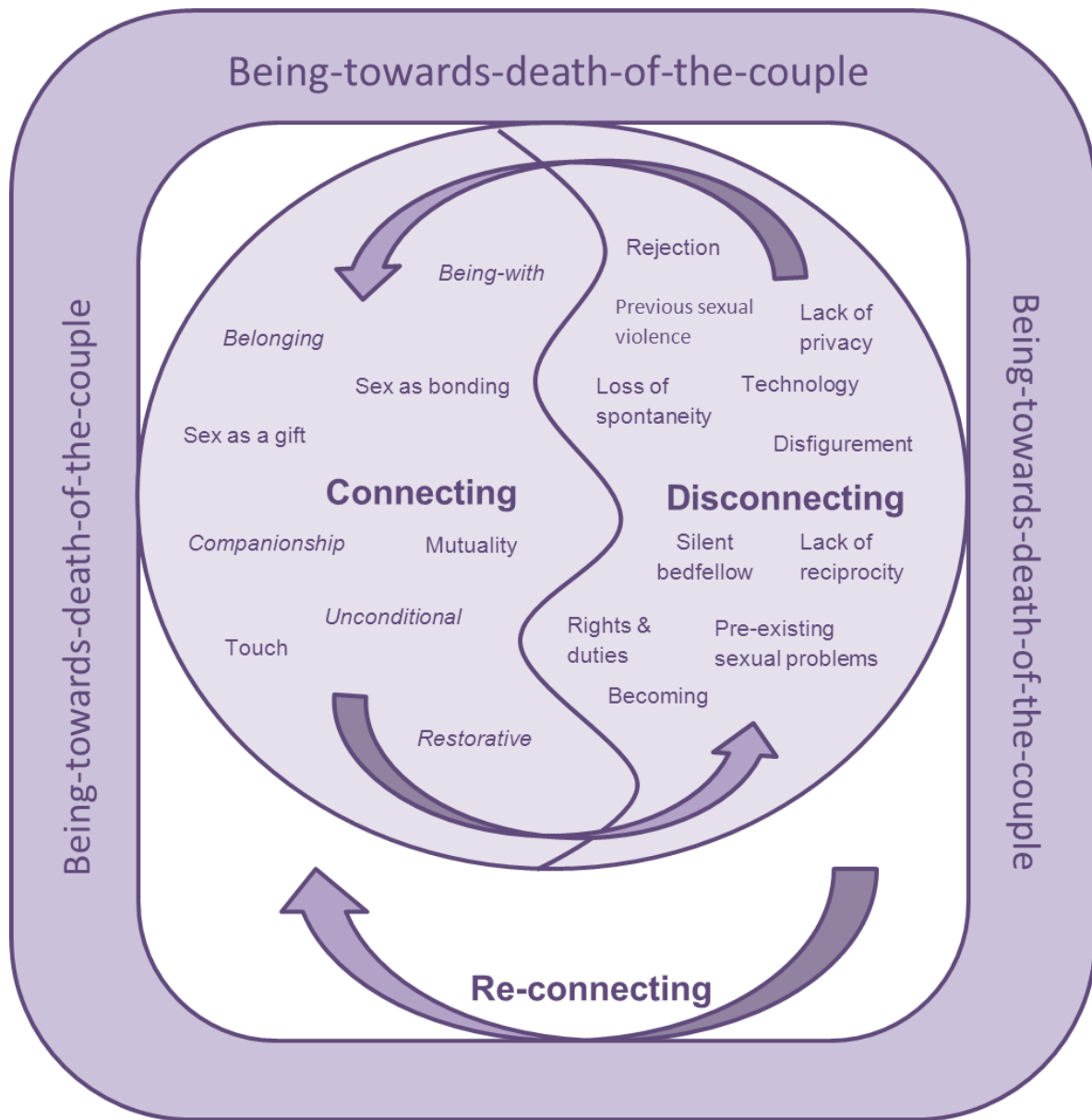
Tom Um, yeah, because I suppose if you feel that your time together is going to reduce, then really you want to be closer together during that period than ever before: and, um, and I think expressing one's love for each other is done in more than just words, I think sharing each other's bodies is a huge way of expressing each other's love but I think words are going to have to be the limits of that relationship unless things change from Deidre's point of view

BT So are you saying that your, knowing that time is limited, that your feelings about love-making have altered?

Tom Oh absolutely, yes, not through want

In this extract, the constitutive pattern of 'being-towards-death-of-the-couple' reveals itself.

Figure 4: Conceptual representation of the themes and constitutive pattern³⁷



³⁷ The constitutive pattern is 'being-towards-death-of-the-couple'.

Are my interpretations justified?

In undertaking this Heideggerian hermeneutic phenomenological study, I have needed to frequently ask myself whether my work was trustworthy, and how I should appraise this. The plethora of terminology that has evolved to evaluate the rigour of qualitative research has created confusion (Morse et al 2002), and some have questioned whether the criteria for appraising rigour in quantitative research should also be used for qualitative studies (Holloway and Wheeler 2002; Morse et al 2002). However, it is important that the framework used to determine rigour should not be a generic one, but should reflect the methodological underpinnings of the study (de Witt and Ploeg 2006; Koch 1996; van Manen 1997).

Morse et al (2002) are critical of researchers who do not recognise their responsibility for incorporating and maintaining rigour. Throughout this study, I have recognised my responsibility in designing and conducting the research, and my intention has been to present this thesis in a form that also enables the reader to assess the trustworthiness of my interpretations.

A framework for establishing rigour

The framework that I have used was developed by de Witt and Ploeg (2006) following a critical review of nursing literature from 1994 to 2004. Designed specifically for hermeneutic phenomenology their 'expressions of rigour' are: 'balanced integration', 'openness', 'concreteness', 'resonance' and 'actualisation'.

Balanced integration

Balanced integration requires that the research methods are supported by the appropriate philosophical concepts (de Witt and Ploeg 2006). It is imperative that there is congruence between the methodology and the method (Baker et al 1992; Maggs-Rapport 2001; Wimpenny and Gass 2000), and Morse et al (2002) argued that it is insufficient to state that an audit trail has been kept, without demonstrating the rationale for decisions that shaped and directed the research within the study's design and implementation. In Chapter 2 and this chapter, I have made transparent my methodological decisions (Koch 1996) in selecting a hermeneutic methodology, in the choices I have made in recruiting participants, and in gathering and analysing the data. My intention has been to

demonstrate methodological coherence in my endeavours to understand the lived experience of sexuality and intimacy for people living with life-limiting illness.

The interpretations I have drawn also reflect the philosophical tenets (Annells 1999; Cohen and Omery 1994; Draucker 1999; Koch 1996), but not to the extent of dominating the voices of participants (de Witt and Ploeg 2006).

Openness

By opening the study up to scrutiny (Kahn 2000) in the ways described above, openness and balanced integration reflect the processes undertaken (de Witt and Ploeg 2006). Throughout this study, I have asked myself whether the methods of data collection and analysis were appropriate and thorough (Mason 2002) and whether my interpretations extend beyond my pre-suppositions. I have been mindful of this throughout my journey towards understanding what sexuality and intimacy mean for people living with a life-limiting illness.

Openness also involves the researcher's attitude towards the phenomenon of enquiry (de Witt and Ploeg 2006). As Heideggerian hermeneutics "locates the unit of analysis in the transaction between participant and interpreter" (Koch 1995:834), reflexivity is an integral part of the hermeneutic circle. As described in Chapter 2, I have brought to this study my pre-suppositions about the meaning and value of sexuality. It is by explicating the pre-suppositions of the researcher alongside the narratives of the participants, with a description of how these viewpoints are merged (Draucker 1999), that the reader is able to assess the influence of the researcher's thoughts and actions upon both the data and subsequent interpretations (Koch 1996).

In order to show my position in co-constructing the data (Koch 1996; Lowes and Prowse 2001), I have retained my voice in some of the interview extracts I have presented³⁸. I have also included extracts from my journal where I have opened myself up to self-scrutiny and reflected upon the challenges I faced. By doing this, I have demonstrated how my own pre-suppositions have merged with those of the participants. This will subsequently influence the reader's own interpretations.

³⁸ This has been kept to a minimum so as not to distract the reader.

Concreteness

Concreteness refers to the relevance of the 'findings' for everyday life (de Witt and Ploeg 2006; van Manen 1997), other contexts (Holloway and Wheeler 2002) and their application to practice (Annells 1999; de Witt and Ploeg 2006; Ray 1994). My intention in undertaking this research was to gain further understanding about the experience of living with a life-limiting illness in order to inform healthcare practice.

My intention has been to shed light on the lived experience of sexuality and intimacy in life-limiting illness in a way that is meaningful for others with similar experiences. I have asked myself whether my interpretations might have wider application (Mason 2002), and whether they might also be meaningful for people living with chronic illness. The relevance of my interpretations for healthcare practice will be discussed in Chapter 9.

Resonance

Resonance encompasses more than a cognitive understanding, but involves the emotional effect of the 'findings' upon the reader (de Witt and Ploeg 2006; van Manen 1997). Are the concepts I have presented in this thesis meaningful (Mason 2002)? Are they "surprising yet obvious" (Morse et al 2002)? I am hopeful that the reader will uncover some shared understanding, or that new understandings will be awakened.

During the course of this study, I have presented my emerging understandings to clinical and academic colleagues at local seminars as well as international conferences (Taylor 2012a; Taylor 2012b; Taylor 2011b; Taylor 2011c; Taylor 2010b; Taylor 2010c). On many such occasions, I have been aware of a 'phenomenological nod' (Mackey 2007:562), where people have nodded in agreement when reading or listening to the interpretations presented (van Manen 1990). This embodied expression of resonance has been further endorsed as healthcare professionals have described being "touched" and "moved". They tell me they have been called to think in a new way, and have gained fresh insights and understanding.

It is particularly important that people from affected communities have an opportunity to judge whether their experiences are reflected in my interpretations (Thomas and Pollio 2002). I have presented my interpretations to conferences attended by people affected by MND (Taylor 2011b; Taylor 2010b), and received confirmatory feedback when individuals have sought me out to share their similar experiences. Bereaved people have also told

me they have 'heard' their own experiences in the data. The echoes of my interpretations in the experiences of others affirmed that there was something justified in my emerging understandings and has provided a "hallmark of trustworthiness" (Smythe et al 2008:1396).

Actualisation

Phenomenological interpretation continues beyond the end of a study (Diekelmann and Ironside 2006). The last expression of rigour, actualisation, refers to the potential for resonance in the future (de Witt and Ploeg 2006). My interpretations have emerged from the lived world and must return to the world of healthcare practice in order for them to be useful (Annells 1999). My responsibility to the participants is to publish these new understandings, and my plans for presenting them to wider audiences are discussed in Chapter 11. I hope that others will "think on" (Smythe et al 2008:1391), and if my interpretations are echoed in the experiences of others, then further affirmation of these interpretations might be possible.

Conclusion

In this chapter, I have discussed the 'thinking' and 'doing' of this study. The decisions I have made in designing and undertaking this study have been underpinned by the philosophical perspectives of Heideggerian hermeneutics. The methods used to gather and analyse the stories have been supported by expressions of rigour in their application. "In the end, as in all phenomenologies, it must be left to the thoughtful reader to decide" (Schmidt 2006:66) on the trustworthiness of my phenomenological interpretations.

Chapter 4: Contextualising my interpretations

Introduction

As explained in Chapter 2, Heideggerian hermeneutic phenomenology does not purport to identify one 'correct' understanding or 'truth' (Smythe et al 2008), for with every revealing there is also concealing (Heidegger 1962). We are constructed by the world in which we live, and at the same time, we construct our world from our experiences (Heidegger 1962). The insights I gained from working with these stories emerged through my interpretations, and are influenced by my pre-suppositions. These fore-structures of understanding have enabled me to make sense of what I have encountered (Greatrex-White 2008) in participants' stories.

This chapter provides context for the 'findings' discussed in the chapters that follow, so includes the context that I bring to this study as researcher and interpreter of participants' experiences. It also includes the context of participants' interpretation that sexuality and intimacy are embodied, relational experiences, which are, for some, perceived as unattainable.

The context I bring to this study

I am a middle-aged, married, Caucasian woman from a middle-class background. I have experienced illness, dying and death with close friends and family members but, as yet, am unaware that I have a life-limiting illness myself, and have no experience of having a partner in this position either.

I have over 30 years' experience as a nurse and currently work as a palliative care nurse in a hospice. When I began my nurse training in 1979, sexuality was not part of the nursing vernacular. There was no recognition that patients might have needs in relation to sexuality. Since then, 'expressing sexuality' has become identified as an 'activity of daily living', being given equal recognition alongside the other activities that include eating and drinking, washing and dressing, and sleeping (Roper et al 1980). Both Webb (1985), and, more recently, Gamlin (2005), have expressed concern that this theoretical stance is not borne out in practice. My own nursing experience concurs with this.

For many years I had recognised the importance of addressing body image in nursing, but the first time that I broached the subject of sex was when I was a district nurse. I was about to re-catheterise a woman in her forties whose catheter had fallen out. I had nursed her for some months, and had even tended her catheter, but had not recognised her as a sexual being. When her husband opened the door to me, I suddenly saw her in the context of a relationship, and wondered whether the catheter interfered with their sexual relationship as a couple. I recognised that this could be an important aspect of nursing care, and summoned the courage to broach the subject. Blushing, I stuttered and mumbled as I asked her how the catheter impacted upon her relationship. The conversation that followed was a turning point for me, as I realised that, if only I had been brave enough to raise the subject earlier, I would have been much better able to support her by discussing the range of options available.

This experience made me reflect on the other patients in my care. I wondered about the woman in her eighties with leg ulcers, and the man in his seventies with an abdominal wound. Did they also have concerns about sexuality that were unaddressed? Little by little, I developed confidence, skills and knowledge in addressing this aspect of people's lives, and began teaching sexuality to healthcare professionals and student nurses in the late 1990s.

In preparation for this thesis, and to help me become more aware of my pre-suppositions, I asked a colleague to interview me about my own understanding of sexuality and intimacy before I began data collection. I have included quotes from this interview (using italics to signify my recorded voice) in order to shed light on these pre-suppositions, to reveal something of the lens through which I viewed the world at that time.

Sexuality and intimacy involve more than sexual expression

My belief that sexuality and intimacy extend beyond physical behaviour is evident in my teaching. I teach sexuality as a holistic concept that includes sexual expression, but is not restricted to this aspect of behaviour. There are other elements to sexuality:

Sexual expression is an important part of sexuality for me ... feeling feminine is an important part of sexuality, and my body image is related to that. When I feel good about myself, sex is not necessarily better, just different.

For me, self-esteem and self-concept are integral components of sexuality that influence sexual behaviour. However, sexuality is not only expressed through sexual behaviour; intimacy is also an important means of expressing sexuality:

It's not just about sex ... Skin to skin contact is important; it doesn't have to be sexual touch to be intimate. Sitting side by side, touching forearms can be lovely.

The intimacy that I described here might suggest a pre-supposition that intimacy is constrained to physical acts. However, my view of sexuality extends beyond this:

The freedom to enjoy and express sexuality does not necessarily involve sexual behaviour, as sexuality is expressed in how we dress, how we feel about ourselves, our relationships with others and how we communicate with those around us.

(Taylor and Davis 2006:35)

This explanation in a co-authored publication illustrates my pre-supposition that sexuality is not restricted to sexual expression. I consider self-concept to be an important dimension, and that we express our sexuality when communicating with others.

Sexuality and intimacy as open communication

I view intimacy and sexual behaviour as means of communicating between partners. This is often unspoken, but when a familiar means of communication is problematic, for example in times of illness or pain, spoken words can sustain this form of communication between partners:

The saddest thing is if people can't talk about it as a couple. Just saying, 'I need you to hold me', or 'I know it's uncomfortable to have intercourse, but can we touch in some other way instead?' is so important.

My view that communication is a two-way process is evident in the following extract:

A relationship is the combination of two people. It involves expressing what you need, while also really hearing what the other is saying. This needs working at in a relationship.

The open communication I have described here involves not only voicing one's own needs, but also hearing and valuing the needs of one's partner. I do not see this as pre-given within relationships, but something that requires effort.

Sexuality and intimacy as conditional rights

Over the years, I have grown beyond my conservative and Catholic upbringing, and have come to value difference in sexual identities, orientations and practices. However, there are still some constraints to this unequivocal acceptance, as indicated in my interview:

Everyone has a right to express themselves sexually in the way that they want to as long as it doesn't harm someone else ... Within a consensual relationship, anything goes.

My respect for autonomy and individual choice is evident here, though within the constraints of non-maleficence. I recognise that sadomasochism is, for example, a form of sexual expression that some enjoy, but only deem this acceptable when these acts are truly consensual. I do not recognise rape or sexual abuse as valid forms of sexual expression.

This belief that everyone has a right to express themselves sexually is not, however, constrained to matters of consent. My belief that everyone has a right to intimacy has caused me to question the institutional barriers imposed by an adult hospice. In 2005, I undertook a bed occupancy audit and confirmed my suspicion that younger patients were given preferential allocation of single rooms (Taylor 2007). I was further concerned by finding that the 'family room', which had the facility of placing a second bed for a partner alongside the patient's bed, had been exclusively allocated to patients less than 60 years of age:

Whether this exclusive use by younger patients reflects an assumption that older patients and their families do not have the need for intimacy would require further study.

(Taylor 2007:149)

I have included this extract to illustrate my pre-supposition that physical intimacy is not a domain of younger people. I believe that older people also have rights and needs in

relation to sexuality and intimacy that should be recognised and respected by healthcare professionals.

Concluding points

We make sense of the world from within it, not while detached from it (Heidegger 1962; Maggs-Rapport 2001; Racher and Robinson 2002). The pre-suppositions that I have illustrated here are, of course, not static. They have been influenced by intervening experiences, which include conversations with the research participants in this study, and the thinking and writing of this thesis.

I have interpreted people's experiences within the context of the conversations we shared, but we each bring our own values, attitudes and experiences to research (Brecher 1970). By explicitly acknowledging these pre-suppositions which characterise the lens through which I view the world, my aim is to enable "readers to make their own judgements about the trustworthiness and credibility of [this] study" (Smith 1999:363). However, whether we are the author or reader of this work, neither of us is truly naïve.

As well as my own pre-suppositions, the 'findings' are embedded within the context of participants' pre-suppositions:

In reflecting back on experience, what is uncovered is not pure experience. Rather, it is remembered experience. There is a tendency to interpret experience in reflection rather than to allow it to speak simply for itself.

(Oiler 1982:179)

What participants shared with me were interpreted experiences described in the context of our interactions with each other³⁹. These interpretations were influenced by their understanding of sexuality and intimacy as embodied experiences.

Sexuality and intimacy as embodied experiences

A requirement of phenomenological research is that participants have experienced the phenomenon in question (Creswell 1998; Moustakas 1994). It is not usual to study two phenomena concurrently, and my initial intention had been to focus upon 'sexuality'.

³⁹ This is discussed further in Chapter 10: Challenges experienced and lessons learned.

However, despite the holistic definitions of sexuality in the healthcare literature, my experience teaching healthcare professionals is that they tend to equate 'sexuality' with sexual behaviour, and I imagined that this might also be the case for patients and their partners. I believed that adding 'intimacy' would ensure that people described a breadth of experience extending beyond sexual behaviour, so adopted the term, 'sexuality and intimacy'.

Despite this, it would appear that people understand sexuality and intimacy to be embodied sexual experiences. This initially became apparent when some of those who chose not to participate explained their reasons on the reply slip:

Sex. What's that? Note the age group.

(Patient aged 61-70, gender not stated)

I don't feel my input would be of any benefit to your study. Any sexual or intimate contact stopped long before my husband's diagnosis. I would like to have helped if circumstances were different.

(Female partner, aged 51-60)

I had not mentioned sex or sexual behaviour in the invitation letter or information sheets, but these responses showed that people equated sexuality and intimacy with embodied experiences. This interpretation was also apparent in the stories participants shared during the interviews, and is shown in the embodied experiences of connecting, disconnecting and re-connecting that are discussed in the following chapters.

Sexuality and intimacy as relational experiences

Dasein, by its nature, is always in relationship with others (Heidegger 1962); "permanently intertwined ... even when it feels alienated or lonely" (Harman 2007:61). All experiences are therefore understood in relation to others. Hence even when someone is single, "others are conspicuous by their absence" (Taylor and de Vocht 2011:1579).

The title of this thesis is 'couples living in twilight', yet some of the study's participants were not in a partnered relationship. My intention had not been to exclude those who were single or divorced, but to study Dasein in its "average everydayness" (Heidegger 1962:38). My aim was to understand the features of sexuality and intimacy that are understood and

shared by all, regardless of their relational status. What has become clear, however, is that sexuality and intimacy are understood as relational experiences; people understand sexuality and intimacy within the context of their own lifeworld.

Kim described herself as “a spinster” at the age of 46. Her long-term relationship had ended before her diagnosis of MND and she did not envisage being in a new relationship:

It is difficult to go out there and get into a new relationship, especially now. I'm quite lucky 'cause I've got a long prognosis, I think. How does a bloke, why would he want to get into a relationship with a single woman who has got a life-limiting illness? You're not going to be a really good catch are you?

Like other ‘patient’ participants who were single, divorced or widowed, sexuality and intimacy were still part of Kim’s lifeworld even in their absence. Her diagnosis heralded an end to the prospect of forming a partnered relationship. Although all humans will one day die, our tendency is to make plans for a future as though we will be alive. Even though Kim was relatively well (indeed, she continued to work part-time), she anticipated a future of disability and dependency, which over-rode this natural human tendency to plan for the future.

You feel insecure being by yourself, well a little bit, but in a partnership you would. 'Cause you'd think, 'oh my God, I'm going to be burden on that person now'. Because in a couple of years' time they're going to be pushing a wheelchair, having to feed and stuff like that and the other person's not going to not feel like a woman are they, they're just going to feel like a patient ... they're just going to feel like an ill person.

In this extract, Kim seemed unable to speak of her future in the first person; it was perhaps too dreadful to consider her own future “like a patient” or “an ill person”, and no longer “like a woman”. Paradoxically, she imagined that the insecurity she felt being single would be exacerbated if she were in a partnered relationship. This adds further context to her description of herself as “a spinster” and not a “good catch”, and extends the metaphor of couples living in twilight. Twilight is the time of day when the sun falls just below the horizon. On the horizon of Kim’s life ahead of her, she could not imagine any possibility of forming a partnered relationship. In her being-towards-death, she was unable to see dawn as a possibility because her life-limiting illness restricted opportunities for forming new relationships.

Although life-limiting illness was a barrier to forming partnered relationships, it was not the only aspect of people's experiences; other factors were at play that rendered sexuality and intimacy unattainable.

Sexuality and intimacy as unattainable

Blagbrough (2010:37) argued that "certain cancers are likely to have greater impact on sexuality as they involve sexual organs, for example penile". Perhaps because it is an uncommon malignancy, there has been a paucity of research on the effect of penile cancer on quality of life. However, a review of six published studies between 1985 and 2008 found that penile cancer has a significant effect on mental health and has profound psychosexual effects (Maddineni et al 2009). I therefore assumed that, for Ivor, who had been diagnosed with penile cancer, and had his penis removed four months before the interview, that this radical surgery would have assaulted his sense of manhood. I was surprised when Ivor explained that his own self-concept and self-esteem were, for him, of greater significance than his disease and prognosis:

Ivor I never thought of myself as much of a man (pause)

BT Has this [removal of his penis] changed that at all?

Ivor No.

For Ivor, the removal of his penis did not emasculate him because his sense of his own masculinity was already limited:

BT You said you're not a very sexual person, can you tell me a bit more about that?

Ivor ... it's hard to put into words this. I am attracted to women, I'm not homosexual, but, I find it difficult to imagine that women would be attracted to me. So therefore it's difficult to make relationships. It's not just the cancer with me. It goes back deeper than that (crying).

BT I think when I met you last week you mentioned that your [excess] weight had something to do with that?

Ivor Yeah, I've always been conscious of my weight (crying). Sorry, could you get me another tissue? (Pause while he wiped his eyes). I'm frightened of rejection, I think. Frightened of rejection. Humiliation.

Ivor described how his self-concept and fear of rejection impeded relationships. He understood that this was an issue prior to his diagnosis, and that his terminal cancer was not what prevented him from forming partnered relationships. For Ivor, these were important experiences to share; he anticipated that he would die that night⁴⁰ and still wanted to take part in the interview⁴¹.

Even though Ivor described issues of self-concept and self-esteem that are evident in a variety of definitions of sexuality (Gamlin 2005; Hodge 1995; Royal College of Nursing 2000; Taylor and Davis 2006), it is evident from his description that self-esteem and body image influence the formation of relationships (Cooper and Guillebaud 1999). Like Kim, Ivor believed that he was unattractive to others. They both perceived sexuality and intimacy to be unattainable because they were construed as relational, embodied experiences.

Conclusion

All understanding is contextually situated:

An interpretation is never a pre-suppositionless apprehending of something presented to us.

(Heidegger 1962:192)

People interpret their world through their pre-suppositions, their fore-structures of understanding. This does not only apply to me, the researcher, and to the reader of this work, but also applies to the research participants themselves. Their understandings of sexuality and intimacy as they have lived them have been influenced by their "preliminary frame of reference" (Sembera 2007:90).

⁴⁰ From my nursing experience in palliative care, I felt this was unlikely. Ivor was not expecting visitors during the time we had set aside for the interview, and appeared well enough to take part.

⁴¹ He insisted by saying, "this is important to me". Ivor died 10 days later.

This chapter has shown that sexuality and intimacy have not been interpreted by participants as holistic experiences that include social, psychological and physical elements *equally*, but rather as embodied experiences centred on sexual behaviour within a relational context.

The following chapters present what has been revealed in the telling of people's experiences. The prism of people's experience has many facets. The ones described here are not all that there is to this aspect of these participants' relationships; they are what called to me as they shared their stories at the time in which they did.

Chapter 5: Sexuality and intimacy as connecting

Introduction

The previous chapter has shown that sexuality and intimacy are experienced as relational, embodied experiences. The narratives that I have gathered from participants in coupled relationships shed further light on this. For these couples living with a life-limiting illness, the essence of sexuality and intimacy appears to be one of connecting. This chapter presents the first of the themes, and discusses the lived experience of 'connecting' for couples living in twilight.

In order to uncover what is understood by connecting, it is first helpful to consider expressions of sexuality that do not constitute connecting. This chapter considers the role of masturbation before presenting participants' experiences of connecting through sexual and non-sexual touch. Within the theme of connecting with each through sex, the sub-themes of 'sex as bonding', 'sex-as-a-gift-for-the-other' and 'sex as mutual exchange' will be explored. Finally, new possibilities for being are discussed in the theme 'connecting in the shadow of impending death'.

Masturbation as a poor substitute for connecting

Although masturbation is a valid means of expressing sexuality (Adams and Painter 1995; Kaufman et al 2003), none of the research participants mentioned masturbation until I first broached the topic. At the time, I believed that their silence reflected a higher level of sensitivity for sexual practices that might be considered taboo. However, their silence seems to have held greater significance. Participants may not have volunteered masturbatory practices because they were not important means of expressing sexuality or intimacy. When participants explained the role that masturbation played in their lives⁴², I began to more fully understand the experience of 'connecting'.

Masturbation was not something that Michael had done throughout his married life, but was something that he had come to rely on more since the frequency of sexual intercourse

⁴² These participants did not refer to mutual masturbation; they described it as solitary activity.

with his wife had decreased (due to her illness) and his own libido had reduced (due to medication). He used masturbation to maintain his sexual relationship with his wife:

It's [masturbation] not very frequent but it does happen, to keep everything working. Almost as basic as I go swimming to keep the shoulders and the hips going, you know, it's in that aspect I view it. Not because the frequency [of sexual intercourse] is extending, therefore I've got to satisfy myself, it's more to keep things going so that when we do make love it works from my end.

Michael did not use masturbation to meet his own sexual needs, but to maintain sexual potency. It was not only men that described masturbation in this way. Stella also described using a vibrator in the past when her husband had been abroad:

To keep things working for when he came home.

This view of masturbation was supported by a woman in Potts et al's (2003:706) study, who believed:

If you don't use it, you will lose it.

In addition to maintaining function, Sean described the beneficial effect of masturbation on his own confidence, but recognised that it did not provide what he needed:

It's the intimacy and the closeness that I hanker for rather than just the sex, because I could go anywhere and get sex. You know, you can go and pay for it down the road, you could ... it's not that side of it that's missing, but the intimacy and you know, masturbating doesn't give you that. But also if, after what happened at the start of the relationship [he experienced erectile dysfunction], it just gives me confidence (whispers) it still works. It's like running. If you go out running, you know, if you stop running for six months, you're going to struggle when you start again.

Both Sean and Michael used masturbation as a form of 'exercise'. It maintained function and provided reassurance they would still be able to have intercourse with their partner. However, masturbation was not a substitute for the intimacy that sex with their partner provided; it was "a poor second, a very poor second" (Jim) to 'being-with' as a couple through sex.

Research by Kinsey et al (1953; 1948) found that masturbation in both men and women considerably reduced after marriage, though for many did not cease altogether. They suggested that this was because marriage provides “a more convenient source of sexual activity” (Kinsey et al 1948:281); many men and women returned to masturbation after divorce or widowhood (Kinsey et al 1948). However it is not merely a matter of convenience; a review of anthropological studies around the world found masturbation to be considered “an inferior form of sexual activity” (Ford and Beach 1952:156).

Berger and Luckmann (1966:202) argued that “man is driven by his biological constitution to seek sexual release and nourishment”. Although the focus of their argument was that sex is a form of sexual pleasure, their use of the word ‘nourishment’ suggests more than sexual enjoyment, but also something that is sustaining. For this study’s participants, any ‘nourishment’ that was gained from masturbating was considered inadequate in comparison with that derived from sexual intercourse with their partner. Although sexual aids and masturbation had a function, they were considered a poor substitute for the union of sex with another.

Connecting with each other through sex

Wells (2002:121) suggested that:

Sexuality is much more than the act of sex; it is the need to be held, to be intimate and ultimately to feel loved.

However, Michelle stressed that the importance of sex should not be negated:

We used to kiss and cuddle and I think all that’s important, but for Dave sex was just as important. I think to say to someone don’t worry about sex anymore is a ridiculous comment, especially for someone as young as Dave.

Not all participants needed sexual intercourse to maintain connecting with their partner. However, regardless of age, sex played an important part in the lives of many. Sexual acts held a variety of meanings; sex was seen as a means of bonding, as a gift for the other, and as mutuality. Each of these sub-themes will be discussed in turn in order to understand the theme, sexuality and intimacy as connecting.

Sex as bonding

Bonding takes place through the expression of sexuality through sex (Lion 1982; Pratt 2000; Yaniv 1995). Many participants described sex as “bonding”:

It [sex] drew us closer and closer together as the years went by.

(Barry)

It [sex] is part of keeping bonding together, isn't it? It's always something that has been important to us, so if it's taken away from you then it would be; the partnership would be obviously changing.

(Nick)

This notion of sex (copulation) as bonding may reflect words' linguistic origins. 'Copulate' derives from the Latin, '*copula*' (Onions 1983:423), meaning a tie or bond (Onions 1983:441). It is notable that the verb, 'to couple', means to fasten, link, join or unite (Onions 1983:441), and the noun, 'couple', means two items of the same kind (Onions 1983). It is perhaps, therefore, unsurprising that sex is seen as having a unifying role in creating and sustaining coupled relationships.

Gagnon and Simon (2005) found that, in new relationships, sex binds the couple together through sexual gratification. However, participants in this study who were in long-standing relationships described the sustaining effects of sex as a bridge between two worlds, connecting the world of one person to that of the other.

Bowlby (1979:127) described a “propensity of human beings to make strong affectional bonds to particular others”. His theory of attachment proposed that the affectional bonds which babies and children develop with their parents are not limited to childhood (Bowlby 1979). As children move into adolescence and then adulthood, these parental bonds are replaced by enduring affectional bonds with another adult (Clulow 2001). These “pair bondings” (Weiss 1991:70) hold “profound meaning” (Bowlby 2007:4) for individuals.

The purpose of attachment behaviour is “to maintain affectional bonds” (Bowlby 1985:42), and renewing these affectional bonds is “a source of joy” (Bowlby 1979:130). Although attachment behaviour was considered by Bowlby (1985) to be distinct from any sexual drive, the bonding aspect of sex that participants have described here suggests that affectional bonds can be strengthened through sex. Indeed, sexual intimacy provides:

A platform of security from which the couple can nourish itself.

(Orbach 2007:16)

These notions of sex cementing or bonding relationships have been part of popular discourse for nearly a hundred years. In *Ideal Marriage*, van de Velde (1930:317) recommended that married couples engage in regular sexual intercourse in order to “intensify their mutual love”. The more recent Relate publication, *Before you say ‘I do’*. *How to be happily married for ever* stated:

If you’re happy together in bed, then you’ve an underlying bond that cements your relationship in other ways.

(Martyn 2003:101)

Ford and Beach’s (1952) cross-cultural research found that the cohesive function of sex contributed towards stability within relationships. It is possible that the participants in this study’s narratives of ‘sex as bonding’ merely reflect popular discourse. However, sex was also described as a means of connecting with their partner that extended beyond the sexual encounter. This is discussed later in this chapter.

Sex-as-a-gift-for-the-other

Some of the participants engaged in sex as a gift for their partner. Even though Sharon no longer gained any sexual satisfaction from sexual intercourse with her husband⁴³, she initiated sex for his benefit:

It’s only like the last few weeks that we have started having sex again. It’s been me that’s initiated it all the time. Not because I want to, but because I feel guilty that I’m, you know, I mean he’s still fairly young, he’s only 50 ... and I just feel so guilty now that there’s been no sex. (Pause) So that’s why I’ve started making the first move again ... He says it doesn't worry him, but I know that all men, I mean he's still a fairly young man so I'm sure it must, he must still get the urge to have sex even though he doesn't force himself on me at all, but I just feel I need to let him have sex ... I can't say that I'm enjoying it, but I do it for Tony.

⁴³ This might have been due to a number of factors: previous surgery and radiotherapy, a co-existing neurological condition, or psycho-sexual issues and fear of pain.

Sally also spoke of maintaining a sexual relationship for altruistic reasons. She described being able to “do without sex” and anticipated a time when, unless she took a more active role sexually, that her partner’s needs would be unmet:

There will come a time when [he] won’t be able to move his hands, and he certainly won’t be able to move his body, and it will be up to me to initiate any intimacy ... I’ll try to make sure that that part of his life stays as normal as possible ... it will have to be me being more sort of forthcoming about it, instead of just waiting for [him] to make the first move, which is my natural inclination ... I shall do it for him.

From these extracts, one might wonder whether sex-as-a-gift-for-the-other was a female experience. Indeed, notions of “sexuality as a form of service to others” are, according to Gagnon and Simon (2005:136), consistent with women’s socialisation in non-sexual domains. Esmail et al (2010) also found that women whose husbands had multiple sclerosis (MS) participated in sexual activities in order to satisfy their partners’ needs and to boost the men’s confidence.

However, this study has found that altruistic sex is not an exclusively female narrative; men also described sex-as-a-gift-for-the-other. Clive attributed his loss of libido to fatigue, and spoke of the importance of maintaining a sexual relationship:

Before my illness, what was important to me, was to keep my wife happy (laughs) and keep our relationship, you know, interesting, and pleasurable ... More latterly it’s been quite easy not to do it for quite a long time. But my wife is very keen for this, she makes it quite clear that she’s, you know, needs to be attended to and so we occasionally get it together.

It is evident from these narratives that many participants were mindful of their partner’s sexual needs and were prepared to prioritise them even when they themselves did not desire sex or gained little or no sexual pleasure. What is unclear is whether participants who engaged in sexual activity as a gift for their partner were able to do this indefinitely, or whether this unreciprocated gift might, in time, be resented.

Heidegger (1962:158) called the concern we have as we comport ourselves towards others, solicitude⁴⁴ [*Fürsorge*]. The two “extreme possibilities” (Heidegger 1962:158) of

⁴⁴ Instead of solicitude, other authors use ‘concern’ (Heidegger 2010, in the translation by Stambaugh) or ‘concernfulness’ (Sembera 2007).

solicitude are “leap in” and “leap ahead” caring. ‘Leaping in’ for the other is when one acts for someone else, making decisions on their behalf. In contrast, ‘leaping ahead’ acts “not to take away their care but to give it back to them” (Smythe 2011:48).

Heidegger’s (1962) thinking calls me to question where sex-as-a-gift-for-the-other sits on this continuum of possibilities. Is sex-as-a-gift an act of ‘leap ahead’ care? Does it liberate “the other for their own possibilities” (Healy 2011:230)? Alternatively, is sex-as-a-gift-for-the-other an act of ‘leap in’ caring? Might this act of gift-giving inadvertently take something away from the other? Does it deny them the opportunity to give pleasure as well as receive it?

Indeed, survey research has shown that men report greater relationship happiness when they also value their partner’s orgasm (Heiman et al 2011). This would suggest that sex-as-a-gift-for-the-other might not meet the partner’s needs if the gift-giver does not also achieve sexual satisfaction. The remainder of this chapter discusses the phenomenon of connecting, and shows that the pleasure that is given and received is not limited to sexual pleasure. The gift-giver may experience connecting through the act of sex even when they themselves do not reach orgasm.

Sex as mutual exchange

Participants described sex as a means of connecting with their partner through mutual exchange. This exchange involved a number of attributes, including mutual pleasure:

A good sex life is really important ... Because we show each other that we love each other ... I didn’t only do it because [he] wanted to, I wanted to just as much.

(Julie)

Julie went on to describe what sex meant for her:

Feeling wonderful with the person you love very much and enjoying making each other satisfied.

Sex was experienced as a reciprocal activity that involved not only sexual gratification:

Sometimes you think, oh I've just got to have a release and you're doing it purely for sex's sake, but I prefer the other way, you know, it's more intimate and you're both getting pleasure from it ... it makes it much more pleasurable if you're both enjoying it.

(Nick)

These examples of the importance of reciprocal pleasure, from both men and women, refute earlier views that domination and power are necessary for favourable sexual relationships (Ellis 1913; Masters and Johnson 1974).

Kaufman et al (2003:4) challenged the belief that penetrative sex is the "real thing", and expressed concern about the negative message that "orgasms experienced alone aren't as fulfilling as those with a partner" (Kaufman et al 2003:4). However, this study has shown that even orgasms experienced through sex with a partner are not in themselves necessarily fulfilling. Participants drew a distinction between 'sex' as a means of achieving sexual gratification and 'making love':

Making love is about two people, it's not about one.

(Tom)

Masters and Johnson (1970) also differentiated between 'sex-sex' and 'love-sex'. They stated that 'sex-sex' lacks mutuality and is purely for the intention of achieving orgasm. In contrast, 'love-sex' is an expression of love through sexual acts (Masters and Johnson 1970). Tom expanded upon this further, describing 'making love' as an opportunity to "share in each other's emotions". When 'making love', connecting through sexual activity renews affectional bonds. It involves warmth and reciprocity as a means of connecting:

It's mutual. I suppose that encapsulates it most. It's a mutual thing, it's giving two ways.

(Jim)

The amount of intimacy within a sexual relationship can vary from extremely high to virtually non-existent (Leviton 1978). However, connecting through sex as mutual exchange is not devoid of emotional attachment. Unlike the attachment bonds that develop in childhood, in adults, "attachment is reciprocal" (Clulow 2001:3).

Gagnon and Simon (2005:136) found that, for most women:

The pursuit of sexual gratification as something separate from emotional or romantic involvement is not particularly attractive.

It is notable that the examples I have given here are from male narratives. I am curious that none of the women in this study drew a distinction between 'sex' and 'making love'. This might possibly have been due to a shared assumption that, as a woman, I would already understand this distinction, and therefore it did not need articulating.

What is evident is that both men and women wanted more than physical gratification in their sexual relationship. In their being-in-the-world-with-each-other during sex, they sought an emotional connection that was mutually and reciprocally shared. When this was not experienced within their partnered relationship, two of the participants described having experienced connecting through an extra-dyadic⁴⁵ relationship. This extra-dyadic relationship may be evidence of what Giddens (1992) called 'confluent love', which is experienced in a 'special relationship' rather than with a 'special person'.

I was fulfilling something that she needed, I mean there was just something there that she needed. And she was, I mean obviously she was doing me a favour ... I just love that feeling of being wanted ...

(Tom)

This extra-dyadic relationship is suggestive of what Giddens (1992) termed a 'pure relationship'. It did not require monogamy and was contingent ('for now'); there was mutual understanding of "until further notice" (Giddens 1992:63). Indeed, it ended when there was a threat of his wife discovering it. Tom found the equality within this relationship that he craved with his wife. He sought connecting as mutuality, and experienced this sexually in his extra-dyadic relationship. Because he had found the connecting that he craved outside his marriage, he expected and demanded less of his wife:

It was really strange, because it suddenly improved my marriage ... and it was something that was picked up on, Deidre made a comment to me, she said you know since you've left me alone, things seem to be much easier.

⁴⁵ This term is used to indicate a sexual relationship beyond the partnered relationship. I have avoided using 'affair' or 'unfaithful' because of the value judgements associated with these terms.

This extra-dyadic relationship was “a sort of medicine”, not curative medicine, but palliative. It relieved Tom’s sexual frustration, enabled him to connect with another person and reduced his dissatisfaction with his marriage.

I agreed to tell you the story because it might just help in your research ... I felt it would help explain how my relationship with my wife was suffering and yet was allowed to survive ... it was like a medicine actually.

To summarise, the mutual pleasure and mutual exchange that participants gained from sexual relationships was experienced as connecting with another through sex. Whether participants had a sexual relationship with their partner or not, they experienced and valued connecting with each other in non-sexual ways.

Connecting with each other in non-sexual ways

Sex is not the be-all-and-end-all of a relationship

Having described the role of sex in binding a relationship together, many participants stressed that sex “isn’t the be-all-and-end-all” (Stanley) of their relationship:

I think it’s important in anybody’s relationship and some people would say it’s half of the relationship and some people would say it’s only one tenth of a relationship ... I think if you haven’t got that part to a relationship, yeah, I would say it’s about fifth on the list. I can’t live without it completely, it’s just the intimacy really that’s part of a happy relationship, definitely.

(Greg)

Greg described the sexual side of a relationship as being “about fifth on the list” and I was intrigued to learn of the four things that were higher on his list, but he was unable to categorise his relationship in this numerical way. His location of sex as “about fifth” merely indicated that it was not a priority, but it was still an important part of his relationship with his partner. This has been found in other studies (Gott and Hinchliff 2003; Hordern and Street 2007b) and was echoed by a participant in Masters and Johnson’s (1970:210) research, who said:

I just have to disagree that a good sexual relationship is essential to a good marriage. It would be lovely to have a good sexual relationship ... but I feel it is not the mainstay of a good marriage.

“Loving and being loved is ultimately a more powerful human exchange than raw sex” (Webster and Heath 2002:222). As Stanley explained:

We've got into a stage over the last few years that sometimes I go to bed before the wife like, and she'll come in and we'll have a kiss and she'll go into her own bedroom. Then in the morning I'll take her a cup of tea and I'll give her a kiss and it feels as if that's taken the place of everything else. And I feel quite satisfied because I know the love is still there and I know that it's even stronger than it was before. Because now love is what it really is, because sex isn't love ... I used to think that it [sex] was the tie of the marriage, but I've found out that it's not. Sex isn't the be-all-and-end-all ... There's more important things to marriage than sex.

Even though participants spoke a lot about the sexual act, connecting was also experienced through physical contact (e.g. in the form of kissing and hugs), through shared activities, shared memories and mutual conversation.

Connecting with each other through non-sexual touch

Affection and companionship can maintain bonds between partners when sexual intercourse is no longer achievable (Askew and Davey 2004). Research has found that affection, companionship and touch are important ways of expressing sexuality (Hawkins et al 2009; Lemieux et al 2004; Wilmoth 2001). This was emphasised by James:

I welcome it when we do have, when we do have a cuddle it's wonderful. More, much more, I mean the sex, you know, genital sex is of no importance at all to me now. But a cuddle is gold, gold dust.

However, even the participants in this study who were in a sexual relationship still valued non-sexual touch as a means of maintaining intimacy and experiencing connecting (Taylor 2011a). As Tom explained:

When I go to bed at night, to actually remove your bedclothes and to be close and intimate, to me that's something altogether different. It's just something warm and tender and I just love that feeling. It's just nice when the two of you are together, whether you're caressing each other or just close to each other, I think that's

absolutely brilliant and you don't even necessarily have to go through the full act of making love, it's a real connection, it's a real bonding isn't it, it's a real bringing together.

For Tom, "being in someone else's arms and being together and being able to discuss things" were experienced as "a real connection". This involved the freedom of touch without the expectation of intercourse.

To feel that we can have a cuddle without it necessarily having to be followed by a sexual act. So long as there is that companionship and the warmth's still there, I think I put more emphasis on that now ... to feel that the support is not just, you know, something that I have to do because it's my duty ... there is still a feeling of well this is the person I'm with and I want to be with.

(Rita)

Connecting was an experience that was freely given; it conveyed support and a sense of belonging, and did not require anything in return:

I just love the fact that Liz cuddles into me ... it's like coming home, it's like being away for years and years and years, away the other side of the world and going back to the place you were born in, that's what it's like with Liz. She makes me feel comfortable, she makes me feel safe ... She holds me and she, I can't explain it, she loves me for me ... She just loves me for me, she doesn't want anything from me.

(Jane)

Peace (1996) suggested that, although sexual relationships may diminish as a result of illness, relationships can become stronger and couples can become closer. This has been endorsed by survey research across five countries, showing that relationship satisfaction was not dependent upon sexual satisfaction, whereas non-sexual physical intimacy (expressed through hugging and kissing) was important for both men and women (Heiman et al 2011).

What is apparent from the participants in this study is that connecting was experienced 'in the moment'. Stanley explained that it was rare that his wife initiated a hug, and often she did not respond to him when he went to hug her. However, on the occasions when she did, this connecting was restorative:

It's a beautiful feeling ... I don't know whether we pass something between us or what, I don't know. It might be we pass a feeling between us, I don't know. But that is the only thing I can say. I can't really describe anything else, there must be a feeling there. I grab hold of her, she grabs hold of me, there must be something electrical or something that charges between us. That's the only way I can describe it ... It feels as if the worries have all been washed away. And yet I know they haven't.

In moments when couples experienced connecting, nothing else seemed to matter; it was as if time stood still. Connecting erased worries and was rejuvenating:

That lovely warm feeling comes all over you when you hug someone and hold them tightly to you and it's like you're sort of giving them what's inside you, you're passing it over to them. To me that's a much, much more demonstrative way of showing someone how you feel about them [than sex]. It's like being drawn with a magnet, to that person. Oh, I need to give you a hug ... just for that split second nothing else matters. Just for the split second, worries [are] temporarily either on hold or forgotten.

(Sally)

Masters and Johnson (1970:239) stated that touch is a primary form of communication that brings with it sensual pleasure: "touching is part of an intimate dialogue". Through hugging and kissing, the dialogue of connecting was experienced.

This dialogue did not only communicate love, affection and security; it also conveyed apology and forgiveness. In Ellis' (1995) autoethnographic account, *Final Negotiations*, she wrote of her experience when her partner was dying from emphysema; "disharmony disappears for the moment" during sex (Ellis 1995:203). In contrast, Jane did not require sexual contact to maintain connecting; this was achieved through a kiss:

It's an emotional connection between us ... No matter how angry we are I think it's another way that we both know that, just because we're arguing and that it doesn't mean we don't love each other. So that kiss just kind of, that just kind of cements it. That's our closeness ... Bad enough we don't have sex, but if we didn't kiss either, no, can't do that.

For Jane, the thought of not being able to kiss her partner was unthinkable. For couples unable to have sex, kissing and hugging played an important role in maintaining relationships (Taylor 2011a). These forms of non-sexual touch were a means of reaffirming love and provided reassurance:

I think it [a hug] reassures, it just reaffirms sort of contact and love, and you know, support.

(Stuart)

This support was provided by partners in an attempt to minimise distress:

When he's in pain, I mean unless he's in extreme pain, I cuddle up to him to try and, you know, sort of help ... literally just enveloping him really and trying to sort of take some of the pain away but you can't can you ... me cuddling up to him is helpful for both of us really.

(Jacky)

It has long been established that touch can reduce pain (Keller and Bzdek 1986). This is because touch can stimulate nerve fibres which inhibit the transmission of painful stimuli (Carr and Mann 2000). However, what is evident here is that touch was also a means of sharing experience, of being-with-the-other (connecting) during pain.

To summarise, the mutual exchange described previously in the context of sex was also experienced through non-sexual touch. When participants gave and received hugs and kisses, they experienced connecting as an “emotional bond” (Taylor 2011a:437). For many participants, hugging and kissing conveyed more than sex; they were an act of love, rather than lust.

Connecting in the shadow of impending death

Realisation of our own death makes us more aware of our own possibilities for being (Heidegger 1962):

If you feel that your time together is going to reduce, then really you want to be closer together [through sex] during that period than ever before.

(Tom)

It is perhaps unsurprising that this study's participants' experiences of living with a life-limiting condition caused them to re-evaluate the meanings that sex held for them. Esmail et al (2010:19) found that men with multiple sclerosis reported opinions that had changed since their diagnosis:

While they stated that intimacy and closeness were more important than intercourse, physical contact was essential for demonstrating feelings and expressing their love ... A strong bond with their partners was perceived as more important than sexual activity itself; which was a significant shift from their beliefs prior to being diagnosed with MS.

Although sexual intercourse was no longer possible for some of those I interviewed, many retained a sense of connectedness with their partner by new shared meaning. When intimacy was no longer present in a sexual sense, it still formed an important part of many couples' lives, and participants' recognition of their limited remaining life gave significance to their experiences:

It shouldn't be the excuse that I haven't got long to go, but I would like to think we would've done that anyway [cuddling on the sofa to watch a film], but it's emphasised it more, it definitely has ... you just value it more.

(Greg)

If your sexual relationship isn't very frequent because of disability and problems, then I think to have cuddles, just passing by each other in the day, I think is important because I feel that otherwise you can grow quite distant in your physical relationship ... if I can't give sexually or physically then, I can give cuddles ... I think as we become more handicapped I think that that's important because I think it fulfills maybe the fact that your sexual relationship is on the decline a bit. It fulfills another role of physically remaining close ... it's sort of part of feeling, you're part of me. You belong to me, you know, you're lovely, you're cuddly. I think that that is important to maintain if your sexual relationship isn't very frequent.

(Rita)

Hugs and cuddles were valued as a means of connecting in the shadow of impending death. They conveyed a sense of belonging and became increasingly important when sex was less frequent. Hugs were also valued as a means of non-verbal communication:

I'm probably a bit more attentive to her now ... because I know that she can't kiss me, so I'll just draw her towards me so she doesn't feel that she's being left out in the cold. And so I think that's probably got better in our relationship ... I suppose it's because she can't actually, we can't actually have a conversation, so I just sometimes go and put my arms around her and give her a hug.

(Nick)

Nick used hugs to prevent his wife being "left out in the cold". In moments of being-alongside her, he drew her towards him so that she experienced being-with. Hugs were used to overcome the separation that her disease had imposed.

The shadow of impending death brought home the permanence of this separation. In moments of connecting, Sally was aware of her partner's impending death and their ultimate separation:

Physically it's no different, but emotionally there's a subtle shift now ... When I'm hugging him, I'm sort of hugging him tighter. I can't think of the right words, it's a, you know when you hug someone and you think, 'oh I do love you, you're lovely' ... it's not pity, it's, I don't know, I suppose it's more of a hold on tightly to you while I can hug ... if I hold you tightly enough, you can't slip away.

Death is present to us if it shapes the meanings of situations we find ourselves in (Wrathall 2005). The future was brought into the present when couples experienced connecting in the shadow of impending death; new possibilities of being were experienced in their "being-towards-the-end" (Heidegger 1962:289).

Conclusion

"Sex for humans is never just sex, *sui generis*" as it is overlaid with meaning and significance (Plummer 2005:xiii). For many participants, the significance of their sexual relationship had changed before the onset of a life-limiting illness. As their relationship developed, sex ceased to be "the emotional centre of experience" (Gagnon and Simon 2005:231). Although earlier research has shown that coital rates declined steadily throughout marriage (Gagnon and Simon 2005; Kinsey et al 1953), sex continued to be important for many participants in this study, including those who had been with their partner for many years.

Sexuality is “an extraordinarily rich continuum” of expression that involves “affection, closeness, sex and touch” (Dallos and Vetere 2009:92). This study has shown that sexuality and intimacy are experienced as connecting with a partner. Connecting is a quality of relatedness. It involves more than meeting sexual needs; it conveys a sense of belonging and is experienced as mutuality. Both men and women valued holding hands, hugging and kissing as means of connecting with their partner, and living with a life-limiting illness influenced these perspectives. Connecting through sex and non-sexual touch were restorative. They provided reassurance of love that endured despite physical ailments, and of being-with while living in the shadow of impending death.

Chapter 6: Sexuality and intimacy as disconnecting

Introduction

Being-in-the-world is always in relation to other people (Heidegger 1962). For these couples living in the twilight of their years, moments of connecting were accompanied by moments of disconnecting, as they experienced 'distance' in their coupled relationship.

This chapter discusses the influence of prior experiences and the many barriers to connecting, which contributed to partners disconnecting with each other. These barriers to connecting included the disease itself, the treatment received and equipment provided, as well as institutional barriers. Within the context of these barriers, disconnecting was experienced as a legacy from the past, as rights and duties, as lack of reciprocity and as rejection. For some, disconnecting was experienced through disfigurement, through becoming a 'different' person, and through becoming a patient or carer. The final sub-theme in this theme of disconnecting that will be presented is 'sexuality and intimacy as silent bedfellows'. Its further sub-themes of 'disconnecting as misunderstanding' and 'disconnecting as pretending' will also be discussed.

Disconnecting as a legacy from the past

As explained in Chapter 2, experiences are encountered and understood in their historicity (Heidegger 1962). The present is understood in the context of earlier experiences and interpretations (Agich 1995; Racher and Robinson 2002). Just as people's experiences of 'connecting' were construed within the context of their past, for some, the intimacy that they experienced while living with life-limiting illness was impeded by their own or their partner's prior experiences, as well as earlier experiences within their coupled relationship. These experiences included previous sexual violence, and sexual difficulties within the relationship.

Previous sexual violence impeding connecting

For some of the participants in this study, connecting was impeded by previous sexual violence. For example, Jane's sexual relationships were marred by childhood sexual

abuse. These prior experiences were 'brought' into the present as she experienced living with terminal cancer:

Jane I hate being touched. I cannot stand it. I hate it. I hate anybody coming near me, sexually. I can't stand it. I hate it. I freak. I freak now with anyone mucking about goes to touch me.

BT Mmm (Pause). Goes to touch you, sexually?

Jane Yeah, sexually. I just can't, it's just, phew. It's just not me, and that's me being really honest. I just don't like it. It does absolutely nothing for me. It doesn't turn me on. It doesn't arouse me. Nothing.

The effect of these experiences upon Jane was absolute. She was not aroused by her genitals being touched and was repulsed by this intimate touch. This had not stopped Jane enjoying stimulating her partner and providing her with sexual pleasure, but did limit opportunities for connecting because the mutuality described in Chapter 5 was missing. Since her illness, however, this had changed:

Liz and I could make love for hours, you know, and now it's just, there's nothing there now. Not in a bad, it's just not happening. And I know Liz feels it, I really do, I can sense it, I can sense it in her body, everything, I can sense the way she moves when we're in bed or if I touch her somewhere and it's like I can sense it and I'm thinking 'shit', because then I think it's not fair on her because I can't carry through with it and I **hate** that feeling ... My body will just, click, that's it forget it, I'm not interested, stop. And then that means that I've started to make love to Liz, and I'm pulling back ... I love Liz, I still find Liz attractive, she's still who I want to be with, she's still who I want to cuddle up to, she's still who I want to make love to and my body's just like, 'no'.

The disconnecting that Jane described was complex. She felt that the cancer and her increased weight might be implicated, though recognised that her history of sexual abuse brought about a 'switch being flicked' at moments of sexual intimacy. This impeded connecting between her and her partner.

Because childhood sexual abuse involves an abuse of trust (Fergus and Keel 2005) and rape involves an exploitation of vulnerability, it is unsurprising that sexual violence impacts upon intimate and sexual relationships. However, the international literature on the effect

of sexual abuse on future relationships emphasises the complexity of any causal relationship because of confounding socio-demographic factors (Fergusson and Mullen 1999). What is clear, though, is that childhood sexual abuse is a risk factor for sexual problems in adult life (Di Lillo 2001; Leonard and Follette 2002; Rellini 2008) and diminished sexual satisfaction (Leonard et al 2008). The influence of the past on the present was clearly shown by Jane.

The influence of prior experiences on connecting did not only involve physical violence. Other participants spoke of the lasting effects of previous sexual difficulties on connecting.

Pre-existing sexual difficulties impeding connecting

Not only were people experiencing the ravages of illness, some participants described significant difficulties within their sexual relationship that arose before the onset of disease. These prior difficulties in the relationship influenced how people made sense of their experiences when living with life-limiting illness. Some recognised their own part in these problems, whereas others attributed the cause to their partner.

Stella attributed the breakdown of her sexual relationship with her husband to a time before his diagnosis:

Stella He would never instigate it. The sexual, and the intimacy between us, it always had to come from me ... and I remember saying to myself at some stage, 'right, I'm going to deal with this in some way', whether this is a good way of dealing with it. With hindsight it was **not** a good way of dealing with it because we couldn't talk about it. I said to myself one day, 'right, I'm not going to make the first move and I'm just going to see how long it takes'. Well, that was it. We never really got back to it. And after six months, you know, you can't be bothered and (pause) phew.

BT I see. And do you miss it at all?

Stella Oh, desperately.

Stella had been unable to understand why her husband did not instigate sex, and her decision to 'test' him backfired as it resulted in an end to their sexual relationship. She spoke of missing their sexual relationship "desperately" now that his life was limited, and recognised that their inability to talk about this aspect of their lives was a barrier.

Frances also spoke of being unable to talk with her husband about their sexual relationship, and described long-standing difficulties within their sexual relationship that began soon after they were married:

The marriage has been a compromise for a very long time since year two when my mother moved in with us, aged 75.

She described her husband not showing affection towards her and her struggle to establish connecting within their relationship:

I kept trying new things trying to engage him or try to live with him as opposed to next to him ... and he always gave some reason why we couldn't do it, so I gave up. And I suppose I should've persisted but I've tried all different sort of strategies and, at some point you just think well, actually, if the other person doesn't want to spend that time with you, you shouldn't be forcing them to.

The disconnecting between Frances and her husband extended beyond their sexual relationship. Frances described becoming resigned to living 'alongside' her husband. The lack of shared time together compounded their "disastrous" sexual relationship and created "deep wounds" that remained raw after his terminal diagnosis.

As discussed in the previous chapter, it is not only women that understand sexuality and intimacy as connecting; men also sought mutuality within their sexual relationship. However, opportunities for connecting eluded Sean because of his partner's "black and white" approach to sex:

Sean I think to her sex is, it's quite a black and white sort of thing to do. She was a bit like that when I met her so, and I have trouble getting that other side out of her. I know it's there, but I have trouble getting that other side out of.

BT Other side?

Sean The intimate side, you know, sort of having sex instead of doing that sort of making love, you know what I mean? Doing all the other things that, you know. I suppose it can seem quite regimented at some point, rather than (lengthy pause)

BT Rather than the foreplay, and the intimacy of enjoying each other's bodies?

Sean Yeah. Yeah (pause). I remember one time she just looks at, she just looked round and said, 'Get on with it' (Laughs). You think, 'that's not really doing it for me'. But, you know, you give in to it.

BT So it's the intimacy that's really important to you?

Sean To me, yeah. And that's the side that's really gone.

Sean described his partner's approach to sex as lacking intimacy and mutuality. Because he had "trouble getting that side out of her", this compounded any insecurities Sean had and created self-doubt:

The fact she enjoys it when it does happen, I can't understand why she's not doing something she enjoys. So that then feeds back into your mind, because then you think, 'Well, yeah, then it must be me'. And then you go around on this circle, it must be me, no it's not me. It must be me, no it's not me. Then why am I feeling so hurt and rejected?

When history is sent to us, it determines how things show themselves (Heidegger 1962); how we make sense of our experiences. The examples above demonstrate how prior experiences influenced how participants made sense of their experiences of connecting within their coupled relationship. Their stories illustrate how experiences are multi-faceted. People's experience of living with life-limiting illness cannot be seen in isolation, for the past is always there, shaping the present.

Disconnecting through loss of spontaneity

Many participants spoke of the disconnecting they experienced through loss of spontaneity. Rita recognised that connecting required more of an effort than previously:

There used to be a sort of spontaneous sort of cuddle ... I think I've become kind of into myself and so concentrating on trying to do what I'm trying to do at that moment. I'll tell you what I can't do, I can't multi-task anymore (laughs) and it really gets me down ... if I was to suddenly give [him] a hug it requires [me] to drop all the things I'm trying to do, concentrate on trying to turn (pause). And also because he hasn't been very well for a number of years, you know, and has had quite a lot of aches and pains, therefore sometimes it would be from his side as well that he, you

know, I couldn't grab him or he'd say 'oh, mind my shoulder'. So I think we need maybe to do that a bit more, to come a bit closer like that.

Difficulty balancing and a need to concentrate on the task in hand limited Rita's ability to give her husband spontaneous hugs and brought about disconnecting. For others, pain and immobility limited spontaneity in their sexual relationship:

I just miss the intimacy and the spontaneity and the not having to plan ... but you've just got to adapt to it.

(Claire)

Although Claire was able to be the active partner and adapt to the changes that her husband's immobility imposed, others experienced disconnecting as loss of spontaneity. This loss of spontaneity was influenced by tiredness for both patients and partners (Gilbert et al 2009), requiring a concerted effort to connect:

The fact that we have had to move to separate rooms, though it has its advantages that we both have a much better night's sleep, it also has the disadvantage that if I'm all settled in bed and comfortable I think I can't be bothered getting out of bed now to go into the other bed.

(Rita)

While Rita was able to make the effort to maintain connecting through sex, Bert was not. He had experienced erectile dysfunction following surgery for cancer, and described loss of spontaneity in his sexual relationship as a deciding factor in abandoning treatment for impotence:

The main thing, I think, the fact that we had always done it on a spontaneity basis and that spontaneity was no longer available ... Neither of us liked the idea of [me] having injections [to create an erection] but I think it was the lack of spontaneity which was the main thing.

Once the spontaneity that was fundamental to Bert's sexual relationship had gone, celibacy seemed the only option. If spontaneity is believed to be a requirement for sex, then it poses challenges for those who would need to plan (Kaufman et al 2003) due to disability, fatigue or other symptoms.

These participants have shown that loss of spontaneity is a barrier to connecting. When physical restrictions could not be overcome, disconnecting was experienced through reduced sexual and non-sexual touch.

Disconnecting as lack of reciprocity

The taken-for-granted means of connecting through touch and close physical contact was something that many participants missed. As Claire explained:

I do miss the hugs and all that. We used to sleep sort of wrapped up, and I can't do that now because he's got his mask, and everything, and it is very restrictive.

It was not only her husband's need for a face mask⁴⁶ that prevented them from sleeping inter-twined; his immobile body lay rigid in the bed and no longer moulded into hers. Claire was mindful of his discomfort as she positioned her body alongside his:

[He] lies on his right side and I'll lie behind him, but I can't put my hands over his chest because it's too heavy on his. So it's like, 'where do you want me to put my hands?' sort of thing, you know, and that is really frustrating ... I can't give him a real big squeeze.

This loss of close physical contact was compounded by a lack of reciprocity. As James explained:

When [she] sits on my bed, sort of facing that way in the morning, at right angles, to give me breakfast, I bring the top of the bed up and she lies against me. But it isn't really a cuddle that ... because I can't put my arms around her.

Due to MND, James' body was passive and he was unable to hug his wife in return. Although he enjoyed this physical contact, it lacked the reciprocity that a cuddle required. This need to give (and not just receive) a hug, to be active in the life-world of their partner, was echoed by Paul Brock (2004:258-259), an Australian who wrote about his experience of living with MND:

For an inveterate romantic like myself, not even to be able to hug my wife is so painful.

⁴⁶ Her partner wore a face mask at night that was connected to a machine. This 'non-invasive-ventilation' forced air into his lungs to support breathing.

As Claire explained, the taken-for-granted hugs that couples previously shared became one-sided when one partner was unable to move:

I just miss the intimacy and the spontaneity ... [him] being able to do something to initiate something. Just to be sat watching telly and he can stroke your leg or something. Silly things like that, you know, because I might sit there and I'm stroking his, 'don't stroke my bloody leg' and I'm like, 'oh for God's sake' and I think, I'd love it if you did that to me.

When her husband used to be able to hug her, Claire felt reassured that "everything's alright". The absence of these hugs confirmed that everything was not "alright". They experienced disconnecting as a couple in moments when her husband's inability to reciprocate touch was brought into her awareness.

When living with a life-limiting illness, many participants described needing touch more than previously. After 40 years of marriage, Jacky described a new need to connect with her husband through touch:

[He]'s never been a terribly demonstrative sort of person, so I think I've always, I've always felt that that's been a bit lacking really, you know, he's not the sort of person who'll come up and suddenly give you cuddle or a kiss or something like that, he just isn't that sort of person. So, so it's almost just, you know, I've almost had 40 years of it, really, but it's just the level has changed, if you like (pause). I think they have become more important now. I mean if he was a bit more demonstrative now, it would be lovely, and I try to be but it's very difficult when he doesn't really take to it if I suddenly come up and give him a cuddle.

Jacky described a deep sense of loss that developed once their sex life had stopped; she missed "being as one" now that her husband was impotent, and her sense of loss was compounded by a lack of reciprocity in non-sexual touch.

Like Jacky, Ellis (1995) also spoke of the need for physical closeness and her need to be held by her dying partner:

I long to be physically close to him, not for sex, but for emotional connection.

(Ellis 1995:211)

Jacky was able to hold her husband when he was in pain but, in the knowledge that Bill's life was limited, kisses and cuddles had become "more important". Jacky needed him to be more demonstrative than he had been in the past, and experienced disconnecting through diminishing touch:

I don't know quite how to say it really ... (sighing) it's almost got to the stage where we don't even cuddle as much because, we are just sort of living our lives alongside one another without very much intimacy at all, and I think that is quite hard sometimes. I'm getting used to it but, you know, it's taking a long time ... and I'm not really sure I feel totally okay about it, but I realise this is the best we've got.

For others, their partner's physical discomfort prevented them from connecting through close physical contact:

Sometimes I put his arm round me when he's sitting in his chair, but that's painful for him. I miss that contact.

(Betty)

Because his body hurts, I can't hold him, and I can't get held myself. Both of us feel the loneliness of being in pain separately.

(Ellis 1995:218)

When couples experienced disconnecting through a lack of reciprocity, they were called to re-interpret touch. Physical contact that lacked mutuality symbolised disconnecting and some began to re-interpret their relationship. Both 'patients' and 'partners of patients' experienced disconnecting as a lack of reciprocity. "Being in pain separately" (Ellis 1995:218) and living "alongside one other" (Jacky) were expressions of disconnecting⁴⁷.

Disconnecting as rejection

At times, the lack of reciprocity described above was also experienced as rejection. For many, disconnecting as rejection was an embodied experience. As Tom explained:

⁴⁷ These are discussed further in Chapter 8: Being-towards-death-of-the-couple.

When you're sleeping in a double bed and the other person's got her back to you and doesn't want to know and you're sort of pushed across, there is a form of, there is a feeling of rejection.

It is only when we are confronted with the inadequacies of the body that we are forced to think about what it can and cannot do (van Manen 1990):

In the normal course of events we take for granted the effortless nature of movement ... increasingly my body announces itself through the experience of absence.

(Toombs 1995:12-13)

Tom was increasingly aware of his body when "the effortless nature of movement" was missing:

It [sex] certainly takes your mind off other things that are going on in life ... [but when] it turns into a clumsy act, well then actually it's reminding me the whole time that you've got a problem and you've got to deal with it.

For Tom, sex was an escape from his illness. However, the clumsiness in his movements brought the reality home to him and he was reminded of his condition. He believed that if his wife took a more active role in their sexual life, then the clumsiness of his movements would be less apparent:

I really, really wish that we could sort it out. Because if Deidre was much keener on taking part, then that clumsiness would go away and we would be able to put those things to the side of us, or I'd be able to put them aside.

The implications of Tom's progressive, terminal disease were 'brought home' to him in moments of rejection:

BT You spoke of converting the study into a bedroom. Will you be making that a double bedroom?

Tom No, I don't think so ... we haven't really had that discussion yet. But I suspect, through early discussions, that I will end up being on my own down here. And whether the room's big enough to take a double bed or not, I don't think it's the intention of my wife to move down with me.

BT I see. And your thoughts and feelings on that?

Tom Devastated, yeah, devastated. But I'm trying not to think about that at the moment. And no decision has actually been made on that thus far. I mean, the excuses so far around the conversation is 'well, when we do that we'll have to get a special bed for you', and all this sort of thing, and I'm not sure I want to sleep in a special bed. I'd rather be in my own [double] bed ... it's the only area where it just seems to bring the future home to me. Because unless you're talking, when you're not talking about the bedroom and about what goes on in the bedroom and how you, life to me goes on as normal. But suddenly that's where the normality of life is completely gone.

If, when Tom could no longer climb the stairs, his wife did not join him in a shared bed downstairs, this aspect of the normality of their life as a couple would cease. In recognising this, their future was brought into the present. Tom also realised that his sexual relationship would end if his wife did not take an active role:

... for one reason or another, my wife has always been one that prefers to lie on the bed with me on top, um, well there's going to be a period soon when I'm not going to be able to do that ... and I need her to be much more active in the relationship and if necessary I need her to help with the contraceptive, with the Durex⁴⁸, I need her to help with probably lying on top of me and she doesn't want to know ... somehow I've got to get her to participate in these things otherwise there won't be a sexual relationship there at all because I won't be able to do anything about it.

Tom was impotent to effect change. His wife 'didn't want to know' and he experienced disconnecting as rejection in the knowledge that their sexual life as a couple would cease.

For Bert, surgery had already rendered him sexually impotent. He was no longer able to have intercourse with his wife, but still wanted to maintain sexual connection:

I did suggest it and tried to involve [her] in something where at least she could continue to get physical pleasure out of, uh, association, shall we say. But she was unhappy with that. She felt if it wasn't possible for me, she didn't want to have something on her own; she'd always felt that it was something joint and once it wasn't joint, she didn't want to know ... I felt that I could've stimulated her and got

⁴⁸ Durex is a brand of condom.

some enjoyment out of that myself as well, but she wasn't interested really in going down that route, she felt we'd lost it and we might as well come to terms with it.

Bert's description further emphasises the mutuality of connecting through sex. His wife did not want him to stimulate her once he himself could no longer have an erection because sexual contact would no longer be a mutual activity. This differs from the findings of other research, which has shown that men with erectile dysfunction withdraw all sexual contact to avoid situations they cannot 'complete' (Riley and Riley 2000), resulting in their partners experiencing reduced intimacy (Askew and Davey 2004). For Bert, however, there was disappointment in no longer being able to give his wife sexual pleasure, as this would have given him some enjoyment too, and might have enabled a new pattern of connecting. Bert experienced disconnecting as rejection. He described a non-negotiable decision because his wife had rejected his suggestion; she "didn't want to know".

Like Bert, Stanley recognised that diminishing sexual contact was not solely due to his disease. He pin-pointed an experience that brought an end to his sexual relationship with his wife:

When I was on chemo ... my wife turned round and said, she says I don't want that bloody thing inside me with all that shit in you ... I just turned over and cuddled into her, started playing with her and she just turned over onto her belly and I thought, well that's it. And ever since, I haven't touched her. Oh, we've had kisses and that sort of thing, but I haven't touched her, I'm ashamed to say. It upsets me sometimes, because I feel that I'm letting her down.

Although condoms are recommended to prevent sexual transmission of toxic chemicals for a week after each course of treatment (Cancer Research UK, no date), Stanley's experience shows the far-reaching effects of chemotherapy. Stanley was 78 years old. Even though he recognised the part that his wife and his treatment played in this disconnecting, Stanley was "ashamed" and felt he was "letting her down". He felt that *he* was rejecting *her*. His expectation was that, as a man, he should provide for his wife sexually. Since his surgery and chemotherapy, Stanley no longer had sexual feelings. He and his wife continued to kiss and hug, but some of his remaining life was preoccupied by guilt, hurt and jealousy; "I just can't let it go".

The examples of disconnecting as rejection described here were not exclusive to men. Katy no longer had sex with her husband, and the rejection she experienced was compounded by her partner's silence:

He has never apologised for not having sex. I mean, it's probably been over a year, but he's never once said I'm really sorry that, you know, not having sex or anything ... He's got very selfish, whereas he'll think of himself rather than me or the boys. He's very blinkered at the moment. It's all to do with him.

Katy's partner had a brain tumour, so it is feasible that his change in behaviour (becoming "very selfish") was a feature of his disease. However, for Katy, his lack of apology was experienced as disconnecting as rejection.

To summarise, disconnecting as rejection was experienced through physical separation, compounded by differing perceptions, needs and expectations between partners.

Disconnecting as rights and duties

Some of the participants in this study spoke about sex as their 'right', or as their 'duty' to provide for the needs of their partner. Although Tom spoke of his need for intimacy, and his need for the mutuality and connection expressed and experienced through sex (as discussed in Chapter 5), he also considered it his right to have sex with his wife, and her duty to provide this:

Our sexual relationship has not been fantastic, probably for about 14, 15 years, I mean it's something that's been very much sort of once a month, maybe twice a month, you're my husband, it's my duty.

Tom described his relationship with his wife as "a 95 per cent marriage". This echoes DH Lawrence's (1960) portrayal, in *Lady Chatterley's Lover*, of an 'incomplete' marriage as one without sex. For Tom, only occasional sexual contact also rendered his marriage incomplete:

She denies me what really a couple should be doing for one another ... I think it's a huge part of a relationship ... I don't see why I should be denied our sexual relationship.

It is feasible that Masters and Johnson's (1970:250) description of orgasm as "our birthright" might have inadvertently fed into notion of rights and duty that they guarded against. Although Masters and Johnson (1970) advocated sex as mutual pleasure, notions of 'birthright' might have further endorsed the discourse around sex as a marital obligation that has been supported by both the church (Church of England 2000; The Bible Societies 1976) and the state (Directgov 2011; Ehrenreich and English 1979).

Although Tom had initially used the term 'making-love' when speaking about his sexual relationship, when I, myself, used this term later in the conversation, he corrected me, describing a difference between how they used to 'make love' and how their current sexual contact was merely to satisfy his sexual (and not emotional) needs.

Tom I haven't shed many tears through this, but there's been the odd occasion where it's happened, um (lengthy pause).

BT At times after you've made love?

Tom Yes, oh, totally. And I don't even describe it as making love. You see, that's the problem, whereas before it was the act of making love. I feel now at the moment it's the act of giving me relief, and that's not what it's all about.

For Tom, "making love is about two people, it's not about one". He missed intimacy and was dissatisfied with sex when it was one-sided and purely to meet his needs. Masters and Johnson (1970) warned against touch without intimacy: when it is clear that touch is for the purpose of intercourse, it does not convey "warmth or closeness" and is "a demand for service or yielding to such a demand" (Masters and Johnson 1970:239). For Tom, the mutuality that 'making love' involved was a reciprocal connection between two people, and this was missing from their sexual relationship:

Our sexual relationship has been very much probably to keep me happy more than for her pleasure.

In inauthentic mode, Dasein is subsumed by *das Man* (Heidegger 1962). It would seem that Tom's wife was subsumed by 'the other'; Tom's needs and wishes took precedence over her own. Even though she conceded to Tom's demand for sex, his needs remained unmet. He wanted, and expected, his wife to share sexual pleasure through connecting:

I find it relaxing. It's something that I feel that you can do together and it's just something that you can, you share in each other's emotions but it's not there at the

moment ... I find it difficult to get her to relax and do what she wants to do, and what she wants to enjoy ... Like bringing her to orgasm, or something like that, would be something that I know that she enjoys, and she gets a lot of pleasure out of it, but she won't allow me to do it, and there's a barrier there and I don't know what that barrier is.

The complexity of sexual relationships is highlighted here. There may be a multiplicity of reasons for this couple's fractured sexual relationship that extend beyond the purpose of this study. What is evident, however, is that when sex is taken out of its relational context (as connecting through mutuality), disconnecting is experienced. Even though Tom's wife sometimes 'obliged' her husband's need for sex, it did not satisfy Tom. This was not merely an issue of frequency. When sex is demanded or grudgingly given, the mutuality and reciprocity that defines sexuality as connecting is missing. It is in these moments that couples experience disconnecting.

Technology's role in disconnecting

There is a paucity of literature on the effects of technology on relationships (Taylor 2011a). This study has shown that patients and their partners implicate technology in their experiences of disconnecting.

The disabling effects of enabling equipment

Two studies that have examined the consequences of enabling equipment have considered safety, pain and independence (Social Policy Research Unit 2000), as well as quality of life (Sainty et al 2009). However, both have neglected to consider the impact of such equipment on relationships. Similarly, Toombs' (1995:11) autobiographical discussion of living with multiple sclerosis described being "imprisoned" by her body if she had not had the funds to pay for an electronic wheelchair. However, she only spoke of this equipment in terms of access and did not discuss its effect upon her coupled relationship.

Although I did not explicitly ask about any equipment that people used, participants in this study described how connecting for them as a couple was impeded by the equipment that was intended to assist them in their daily life (Taylor 2011a). Wheelchairs and reclining armchairs were described as restricting access, restricting upon both the frequency and quality of intimate exchange:

I always sort of kiss him goodnight when he's in bed, but just a light kiss. It's quite a difficult act to kiss properly when someone's, you know, always at a distance, in an armchair or something, you can't actually physically manage it very easily.

(Betty)

Restricted physical access, from equipment that is designed to enable, disrupts the normalcy of couples' every day means of "communicating love and affection through touch and close physical contact" (Taylor 2011a:439). Perhaps more profound, was the effect of a hospital bed on the coupled relationship:

Jim In anticipation of this interview, I was desperately trying to remember when was the last time [we had sex]. It must be two years. Because what finally separated us was the fact that I have to live on the ground floor and upstairs is a superb bedroom ... where we spent [many] very happy years in conjunction in this home.

BT So it was that physical separation?

Jim That finally did it.

Jim was unable to move and slept in a hospital bed downstairs, and his wife was alone in their marital bed. The disease (and the hospital bed that accompanied it) disrupted their way of being-in-the-world with each other:

Jim It [sex] was not the centre piece, it was **our** centre piece.

BT Can you explain what you mean by that?

Jim Well, it was thing that united us utterly. And only this damned disease has destroyed it.

The forced separation imposed by the hospital bed destroyed the "centre piece" of their relationship, the sexual relationship that had united them as a couple. Connecting with each other through sex became a distant memory, and both struggled to recall "the last time".

Many years ago, when working as a district nurse, I used to challenge colleagues' assumption that it would be 'best' to move a single bed downstairs when someone was dying (Taylor 2011a). I considered this an unnecessary disruption to their home and could not see any benefit in separating couples who had spent their life sharing the same bed.

More recently, research by Bowden and Bliss (2008) found a profound effect on families arising from the introduction of a hospital bed; the meaning of 'home' was disrupted. As yet, however, there has been no research that considers the impact of a hospital bed on sexuality or intimacy (Bowden and Bliss 2009).

Hislop's (2007) qualitative study with 40 couples found that sleeping together can be "more a 'bed of thorns' than a 'bed of roses'" due to the disruptions to sleep caused by differing sleep patterns. Even though couples were aware of the possibility of better sleep in separate beds, all chose to remain in the shared bed. One person explained that sharing a bed is "a significant part of keeping you together".

Even when one partner was ill, the couples in Hislop's (2007) study prioritised communal sleeping patterns over their own need for sleep. "Sleeping together lies at the core of the couple relationship" (Hislop 2007) as it enables an emotional bond that is sustained through 'pillow talk' and physical closeness. Hislop (2007) concluded that, for many, a shared bed defines and reinforces the couple identity; it is a "symbol of togetherness".

The introduction of a hospital bed disrupts more than the spatial dimensions of relationships. It is a barrier to the intimacy expressed through sex, and intrudes upon the companionship that is expressed through hugs and intimate conversations within a shared bed. When sharing a bed symbolises commitment and togetherness (Hislop 2007), the introduction of separate sleeping arrangements can symbolise separation and becoming apart as a couple. After 40 years of marriage, Betty explained the significance of this loss:

I think if [he] hadn't had MND we'd have continued our life much as it was. You know, there was no change in the way we felt about things with each other ... We still enjoyed sex, so I think if he hadn't had MND we would've probably just carried on and definitely we would have always slept together. I never, **ever** imagined that we would not be sleeping together, which used to shock me when I used to go to friends' homes and they weren't sleeping in the same room, let alone different beds ... It just seemed to kill things once we couldn't sleep together. The first one [hospital bed] was with a fairly ordinary mattress, which was still possible that I could sort of squeeze in. Then he got this, you know, special one that's all moving, you know, and trying to get in there, it's just too difficult.

Electrically operated hospital beds are introduced to people with a life-limiting illness to facilitate access for carers and to enable the failing body to sit up and lie down. At the

mere touch of a button, the bed operates the body that is passive within it. However, technology is more than a set of tools or equipment that are subject to our control (Stenstad 2006), technology is a way of revealing (Heidegger 1977). At times of breakdown, “the normalcy of everyday life is disrupted” (Sloan 2002:159). It is at these times of breakdown that the taken-for-granted of everyday life is exposed and becomes visible (Heidegger 1962). The forced separation imposed by the hospital bed disrupted the normalcy of couples’ everyday means of being-with-each-other, of communicating love and affection through touch and close physical contact. Paradoxically, the hospital bed that was introduced to enable movement and access became a barrier: it disabled couples. Betty had attempted to maintain connecting by squeezing into the bed with her husband, but this was no longer possible.

The connection and bonding brought about by lying together in a shared bed described in Chapter 5 can define and reinforce a couple’s identity. However, even though Hislop (2007) suggested that a shared bed is a “symbol of togetherness”, the move into separate beds does not automatically bring about disconnecting. Michael described how choice is a contextual factor that should not be overlooked:

We actually sleep in separate beds, though we have a cuddle before we go ... she was finding it very hard to turn and to move ... that was affecting my sleep ... and she decided to try and give me a better night’s sleep and decided to go into the room next door and I supported that because it came from her ... And it has, without a doubt, made our life, our nocturnal sleeping pattern better ... And when we decide we need to be in the same bed to make love and so on, she comes to my bed and that, you know, works perfectly well. Sometimes she’ll leave after it and sometimes she’ll stay ‘til later in the night and then leave ... it sounds like an emotionally retrograde step, and somebody could say that. I don’t say that. I think for the management of her disease and the well-being of myself, the carer, I think it’s worked well (pause). I do welcome the extra sleep because caring is very tiring and with my physical condition, sometimes at the end of the day I’m as tired as she is (pause) ... I think possibly the plusses of being apart outweigh the minuses of not being together, you know, to make love more often.

Michael described agreeing to his wife’s decision to move into a spare bedroom and was clear that this was not a “retrograde step”. He could identify clear benefits in terms of

improved sleep even though this resulted in a reduction in their love-making. He went on to explain:

It was a solution that was reversible, you know, and still is reversible.

Michael's involvement in this decision and the potential for reversing it contextualises his different understanding of sleeping in separate beds. I don't know whether his interpretation of their sleeping arrangements would change once his wife became less well and they were no longer able to cuddle or make love in a shared bed. For participants where a hospital bed was needed, it was an irreversible step. There were no discussions with healthcare professionals about its potential impact on their coupled relationship, on disconnecting.

Couples like Betty and Jim described attempts to reverse the disconnecting brought about by separate beds. When Betty could no longer squeeze into her husband's hospital bed because of the ripple mattress, she was creative in seeking a way for them to lie together:

I will say that Betty took me greatly by surprise some months ago now, certainly not exceeding 12, by announcing that she had bought a double bed. And I said 'what on earth are you talking about?' And she said 'it's an inflatable double bed'. And with a good deal of curiosity, and laughter, we put it all up and went on it just once together. But it was no use really. I couldn't do anything for her or to her.

(Jim)

... It was all such a hassle and performance, by the time we actually laid on the bed, we were both exhausted (pause). You know, Jim can't move or do anything and the bed was quite bouncy and I was worried he would slide off, so it wasn't the most successful. But I couldn't think of any other way. Jim said 'why don't we just lay on the floor?' and I thought that would be too hard for him ... I haven't got it out again. I said to Jim the other day 'shall I get it out?' But, oh, maybe another day.

(Betty)

The importance of this experience in their lives is emphasised because both Betty and Jim referred to it, unprompted. Regardless of their age or Jim's failing health, the need to connect prevailed. Betty "couldn't think of any other way", and Jim was even prepared to lie on the floor so that he and Betty could be physically close.

Brock (2004:12), who also had MND, echoed the value of connecting in this way. He described only brief moments of physical closeness once he was in a hospital bed and he and his wife were in separate bedrooms:

She lies against me momentarily on my bed and we pretend, for an instant, that everything is as it once was.

The moments of connecting when lying together in bed, or on a mattress on the floor, are an escape from the reality of disconnecting as a couple. Betty had not given up hope of getting the mattress out again, but Jim died two-and-a-half weeks later.

While this study has shown that hospital beds and wheelchairs do not always enable, disconnecting is not only brought about by a reduction in physical contact. Julie described how connecting with her husband was impeded by her light-writer⁴⁹:

When I want to tell him how much I love him it doesn't sound the same from a machine.

It is somewhat ironic that the communication aid, Lightwriter®SL40 Connect, uses the words 'let's connect!' in its advertising (Churchill, no date). Although these devices undoubtedly do facilitate communication, Julie has shown that they do not always enable connecting. Julie no longer told her partner that she loved him because the electronic, male-sounding words, 'I love you', were not spoken in her voice (Taylor 2011a).

Heidegger's (1977:4) assertion that "the essence of technology is by no means anything technological" calls us to consider that technology is more than a human tool and a 'means to an end'. Technology is a contributory factor in transforming relationships. While the light-writer is a 'voice' for those no longer able to speak, it is also a muffle. The machine 'spoke', but it did not speak in Julie's voice. It was even given the name 'Sally' by Julie and her husband, highlighting that even though the words it spoke were hers, they were not *of* her. The light-writer enabled Julie to participate in the world of others, yet at the same time it silenced her; 'Sally' intruded on their relationship. The light-writer facilitated communication and at the same time was a barrier to intimacy. Like the hospital bed, it both enabled and disabled.

⁴⁹ A 'light-writer' is a portable text-to-speech device which enables people without speech to communicate.

Heidegger (1977) suggested that when we focus solely upon the promise of technology (what it can do), we are blind to the threat it poses. This study has highlighted the importance of considering the meaning technology has for people using it, recognising technology's enabling and disabling effects:

We are delivered over to it in the worst possible way when we regard it as something neutral; for this conception of it, to which today we particularly like to do homage, makes us utterly blind to the essence of technology.

(Heidegger 1977:4).

Disconnecting through Viagra: It only “does what is says on the tin”

The drug, Viagra⁵⁰, is also a technology (Potts et al 2003); it is a tool (Loe 2001) that chemically engineers an erection. Sex has become subject to the medical and technological ‘gaze’ (Foucault 1998), and Viagra is prescribed to fix the faulty machine (the penis). With the advent of this technology, the penis can be regulated and controlled.

Several participants (unprompted) described their experiences of using Viagra. Greg explained that it merely enabled the penis to be ‘ready for use’:

... we occasionally get it together but it's a bit of an effort ... I got some Viagra, which I had to get on a private prescription, because apparently it's not a direct effect of MND, and we've used that once or twice with varying success (laughs). It works in terms of, you know, creating the erection, yes, but if other parts of the ol' system aren't equally excited, shall we say, then it won't necessary result in the outcome that you hope it will.

Viagra served a purpose in enabling Greg to have intercourse with his wife, but when he was not adequately aroused himself, he did not achieve orgasm. Viagra only “does what it says on the tin”.

Katy explained that Viagra posed a further disadvantage as it created an expectation of sexual intercourse that was not always willingly reciprocated:

⁵⁰ Viagra (Sildenafil) is a tablet licensed for treating erectile dysfunction (BMJ Group and the Royal Pharmaceutical Society of Great Britain 2011).

I could be **so** tired and then he'd come up and he'd just want to have sex. And I'm not somebody who would just, you know, say, 'No, I'm sorry Jake, I'm not having it' because I don't like to reject somebody. But then he'd go, 'that was a waste of a tablet', and then I'd feel really **bad** and, oh okay ... there were times where I just didn't want to. He would come to bed late and I'd be half asleep and I'd have to get up early in the morning for the boys and he'd want it, and he'd have taken a tablet without telling me. So he'd still have it.

Katy described a lack of shared decision-making. Her partner did not consult her before taking Viagra, and then expected her to respond to his suggestion of intercourse, whether she wanted to or not. When Katy's partner took Viagra, he expected sex to take place, otherwise it was "a waste of a tablet".

According to Heidegger (1977), the issue with technology is the objectification of Being; under its reign, "everything comes to exist as ready for order" (Mitchell 2011:1). While Heidegger's (1977) discussion of technology focussed upon productive manufacturing, and the harnessing of nature to produce materials and energy, Zitzelsberger (2004) extended this to consider the order imposed upon the body by modern healthcare. Although she did not discuss the order imposed by medication, her work bears relevance in this context.

Viagra worked by calling Jake's body to action and therefore both his and Katy's body were positioned as 'standing reserve', expected to respond. By positioning bodies as standing reserve, their natural resources are revealed and therefore controlled, ordered and exploited (Zitzelsberger 2004:247):

Through revealing the body and its processes in particular ways, other facets and processes become concealed.

When Jake took Viagra and presented his body ready for intercourse, the lack of intimacy within their relationship was concealed when Katy acquiesced. In re-telling her experience, their way of being-in-the-world with each other and the lack of intimacy and equality in their relationship was revealed.

The pressure to 'oblige' described by Katy might be an expression of a cultural belief that it is women's 'duty' to provide for man's 'need for sex' (Dallos and Dallos 1997). However, Viagra compounds this. The pressure to have sex to avoid wasting a tablet and to

appease the male partner was endorsed by women in Potts et al's (2004; 2003) New Zealand study of men and women who had used Viagra. Considering the relational and emotional effects of Viagra use, Potts et al (2004) found that Viagra sometimes brought about sex that lacked intimacy. As one man said:

You could be completely unemotionally involved and yet still have a hard erection, it's incredible.

(Potts et al 2004:496)

Viagra caused a variety of relational effects, and sometimes caused tension and distance within relationships (Potts et al 2004). The increased capacity and focus upon vaginal intercourse brought about by Viagra was not always welcomed, as it sometimes resulted in a reduction in intimacy (Potts et al 2003).

It is ironic that a drug that is designed to enable a physical expression of intimacy can actually have the opposite effect by subverting mutuality and thereby fostering disconnecting. Jim came to realise this on the two occasions when he had taken Viagra:

I could tell that Betty didn't very much appreciate them. They work in the vesicle way [physiologically] but I think she felt they were just a chemical, which is exactly what they are. And we've never pursued them or taken any more since and I don't think I would want to because, whilst it might work physically, it doesn't work in the cross-mutuality that I've referred to many times.

The mutuality that Jim referred to was the connecting that he and Betty had shared throughout their married life. For Jim, Greg and Katy, Viagra did not facilitate connecting. When using Viagra, the human body becomes objectified and phallogocentric notions of sex are reinforced (Askew and Davey 2004) at the expense of intimacy and connecting. The essence of their sexual relationship (connecting through mutuality) was lost when the erect penis became a 'piece' rather than a 'part':

The piece [*das Stück*] is something other than the part [*der Teil*]. The part shares itself with parts in a whole. It takes part in the whole, belongs to it. The piece on the contrary is separated and indeed, as the piece, is even isolated from the other pieces. It never shares itself with these in a whole.

(Heidegger 2012:34)

Viagra is the agent by which a 'part' is rendered a 'piece'. When taking Viagra, the erect penis becomes ready and available for intercourse. However, the chemically induced erection is not 'part' of the experience of connecting; it is merely a 'piece' whose integrity is missing. For these participants, its use was experienced as disconnecting.

Disconnecting through disfigurement

Some of the participants in this study experienced disfigurement arising from surgery, weight loss or weight gain, hair loss or disability. Disconnecting was brought about through disfigurement as the taken-for-granted body was brought into awareness during sex.

Maureen had adjusted to getting undressed in front of her husband since her mastectomy one year ago, but when he touched her during sex, she was conscious of her missing breast and the scar that replaced it:

It's only recently that I've felt comfortable with him seeing me looking odd (slight laugh), rather than I was always covering myself up straightaway ... I haven't, as yet, felt comfortable with having sex ... It's more of a chore rather than a pleasure, if you know what I mean, and I know he gets very frustrated ... I don't like him making, what can I say, a big song and dance about it (touching her scar). It's like, if they like to kiss you up top, you know, and fondle you, it's like, yeah okay, that's enough now sort of thing ... the one that's there's okay but the one that isn't. It's like, don't make a big song, because I know it's there [the scar]; we know it's there, you don't want to make a big issue of the fact, it's like paying it more attention ...

I had asked Maureen what it was like when her husband did kiss her scar. Her response illustrated moments of disconnecting during sex:

It's just do it. That's it.

Maureen recognised that her discomfort about sex might change, though whether she lived long enough for this to be realised is unclear.

Angela, a woman in her forties, had insisted on a breast implant when she had her mastectomy 15 months previously:

Angela It's no longer a breast; it's a prosthesis, really, which just happens to be inside my skin ... I think it's affected my confidence. I knew he

found my breasts attractive and so, it was something that I was quite happy to show off and be in a position where he could appreciate what they looked like. And now on occasions, although he doesn't say anything and he doesn't seem to find them, it, unattractive, it just goes through my mind if we're being intimate, this must look ridiculous ... it's not the same visual impact at all that it used to be and I'm very conscious of that.

BT Is that because of the nipple missing or is it more than that?

Angela It's more than that. It's because the nipple is missing but also because they just don't move in the same way. It's a breast form, you know, it's not a replacement breast, it's a breast form ... in some ways with my clothes on it's an improvement ... I actually think in terms of proportion, now I look better with my clothes on ... but certainly with my clothes off I don't like how I look ... if it's affecting anything it's the intimacy with me and my husband ... I need more reassurance now ... I'll get undressed and I'll turn around and I'll look at him and I'll say 'don't you think this looks really unattractive?' And 'don't you think that it looks really ridiculous?' ... He doesn't really enter the discussion, to be honest; he always just says 'you're fine. You're lovely to me' and that's it.

Angela's breast had been surgically replaced 'in-order-to' (Heidegger 1962) resemble the breast that had been removed and 'for the sake of' (Heidegger 1962) appearing normal. Under technology's pervasive rule, everything becomes replaceable (Mitchell 2011). However, Angela's breast was not replaceable. Surgery had rendered the "breast form" no longer 'fit for purpose'. Although an improvement to her appearance when clothed, the "breast form" was conspicuous and obtrusive during sex with her husband, Angela's attention was drawn to it and it was no longer 'ready-to-hand' (Heidegger 1962):

It revealed itself as a something just present-at-hand [a breast form] and no more.

(Heidegger 1962:103)

Blattner (1992) and Dreyfus (1990) described Heidegger's concept of understanding in terms of competence. We understand a hammer because we can use it (Blattner 1992), and we understand what it is to be a nurse because of being competent to be one.

However, Angela's loss of her breast was not necessarily about role or function. Her breast was symbolic of the taken-for-granted sexual relationship that she and her husband once shared. The playfulness in their relationship was gone because her "breast form" was obtrusive during these intimate moments:

[In the past] If I didn't have my nightie on, I would sit up and I knew that he found it quite attractive to be able to look up at my breasts. But that's a thing I never do now.

Body-image does not arise from the "inseparability" of mind and body (Williams and Bendelow 1998:98), but is, by its nature, social (Schilder 1950). Body-image is "developed and construed in and through social relations" (Williams and Bendelow 1998:99), through comparison to other bodies and our own perceptions of 'normal' and 'ideal'. Body-image is therefore perceived within the world in which we live, the world of our relationships.

In her autobiographical account of living with multiple sclerosis, Kay Toombs (1995:13) wrote that her body "announces itself through the experience of absence". What was once effortless became apparent as parts of her body "no longer belonged" (Toombs 1995:8).

Before her surgery, Angela's breasts did not "announce themselves in this way" (Harman 2007:63); they were an important component of her sexual relationship with her husband. The absence of one breast, and its replacement with a "breast form", was experienced as disconnecting within her sexual relationship as she felt "ridiculous" in her disfigured body. Her husband's behaviour also changed in response to this "breast form":

He doesn't tend to touch the breast form ... he tends to only touch the left breast. It makes me feel if I ever have to have that removed, what then? Then there'd be nothing left and how would he feel about that? And how would I feel about that? ... When we go to sleep, I lie on my left side and he always puts his arm round me and his arm always comes to rest there. And I'm very conscious of the fact there is only one ... I'm conscious of thinking 'thank goodness at the moment that still feels the same'.

When her husband touched her healthy breast, the presence of his touch reminded Angela of her missing breast. She was also aware of the fragility of this touch, and the fragility of her body, as there might come a day when that breast also had to be removed. Her husband's reassurance that she was "fine" was ineffective because she was reminded of

all she had lost. Their sexual relationship had lost its spontaneity and playfulness, and even sleeping side by side symbolised disconnecting through disfigurement. It also brought the future into the present, reminding her of what might yet come.

Studies with women who had surgery for breast cancer have found that breast reconstruction has no benefit compared to mastectomy in terms of body image (Yurek et al 2000) and sexual activity (Schover et al 1995; Yurek et al 2000) one month post-surgery (Yurek et al 2000) and up to nine years later (Schover et al 1995). While fear of the cancer returning might have been implicated for some of the women in these studies, further research has shown that “an altered sexual self” is a key factor in disrupted sexual relationships for women treated for breast cancer (Wilmoth 2001:278).

For Angela, the artificial breast was only a piece of her; it did not belong to her body in the way that a nose belongs to, and is part of, the face and ‘completes the whole’. Unlike cosmetically enhanced breasts that are a matter of choice, surgery for breast cancer disrupts the body’s integrity; the “breast form” that was created to replace Angela’s diseased breast was not a ‘part’ of her. Its relationality determined whether it was a piece or a part - its relationality in the context of her body, and in the context of her sexual relationship with her husband.

It was not only women with breast cancer that experienced an altered sexual self. Julie spoke of the effect of excessive dribbling (due to MND) on her sexual relationship:

BT Has the dribbling had an effect on making love?

Julie No, only that I think about what [my husband] must think.

BT Are you conscious of that at the time?

Julie (Nods) ... It is awful.

BT Have you asked [him] what he feels about it?

Julie No.

BT Can you tell me why?

Julie Because I get embarrassed about it ... It is the worst thing for me.

Julie experienced disconnecting by turning away from her husband during sex so that he would not notice her dribbling. She experienced moments of disconnecting by hiding her disfigurement from him:

I do wonder if he still finds me attractive now ... he used to like me to put on nice underwear and have a bit of foreplay before we had sex. But now I feel ugly and don't want him to see me.

These women described a change in their sexual relationship that had arisen through an altered sense of sexual self. Aspects of sex that they had once enjoyed with their partner had been transformed into moments of disconnecting through disfigurement. For some, sexual relationships can be re-framed over time (Jun et al 2011; Hawkins et al 2009; Wilmoth 2001). However, for those living with a life-limiting illness, there may not be sufficient time to experience these changes. Indeed, as Nick explained, further disfigurement was a possibility:

I'm a fairly visual person in that field [during sex] and it would, if she sort of, as I say, got extremely thin or wasn't able to look attractive then, you know, that might affect things.

Although her husband described having adapted to his wife's PEG (percutaneous endoscopic gastrostomy) tube⁵¹ and dribbling in ways so that "I don't even see it", he was mindful that, as her condition deteriorated, there would be further visual changes that might affect his ability to be sexually aroused. He was uncertain of what the future would hold for their sexual relationship, and this would have the potential for further disconnecting through disfigurement.

Disconnecting through lack of privacy

Three of the participants⁵² in this study were separated from their spouse because they, or their partner, were in a nursing home. They all referred to the importance of privacy in maintaining connecting, and described disconnecting through a lack of privacy.

⁵¹ PEG feeding tubes are inserted into the stomach through the abdomen. They are used when people cannot maintain their own hydration or nutrition (e.g. due to impaired swallowing in people with MND or head and neck tumours).

⁵² Two patients and one partner.

Alongside MND, Gilbert's wife had dementia⁵³. The only opportunity for being alone with her was when visiting her in the care home:

... you had to be on your alert all the time. Even when she'd be sitting there and I'd be sitting on the bed and talking or holding her hand, the door would fly open you know, 'oh are you alright?' 'Yeah, yeah, fine thanks'. And it wasn't sort of right, you know. And, of course, when I got her writing and all this, they'd come in when you're in the middle of doing, you might get her saying the cats' names or something, you know, and she'd be putting 'Polly and, ooh', as soon as the door opened she'd lost it all. It would be gone, you know. It would be nice if you could go somewhere to be able to be together like on the settee somewhere in a room on your own or somewhere where you could kind of hold each other, or just to lay down and be together, something like that, you know. But it never happened.

The privacy that Gilbert and his wife needed for connecting was intruded upon when carers burst into her room. They were unable to have uninterrupted conversations about their shared life together, and there were no opportunities to lie together. Gilbert was bereaved at the time of this interview, and connecting with his wife in this way "never happened" while she was in the nursing home.

The Royal College of Nursing (2011) publication, *Older People in Care Homes: Sexuality and Intimate Relationships*, endorses the need for privacy when partners visit. Their recommendations for maintaining partnered relationships include having 'do not disturb' signs available, and "staff waiting to be invited before entering [bedrooms]" (Royal College of Nursing 2011:2). The extent to which nursing homes have taken on board these recommendations is, as yet, unknown.

None of this study's participants spoke about privacy in hospital or hospice settings, and this was something I did not explicitly ask. However, Lemieux et al's (2004) Canadian study found that cancer patients identified institutional barriers to expressing sexuality in both hospital and hospice environments that included shared rooms and staff intrusion. One participant suggested staff should prioritise "couples spending time together" (Lemieux et al 2004:633) and recommended uninterrupted visiting time that staff also complied with.

⁵³ Cognitive impairment is common in people with MND (Talbot and Marsden 2008). As many as 5% of people with MND also have Fronto-temporal dementia (Talbot et al 2010).

It is important to recognise that the intrusion of staff as a barrier to connecting is not exclusive to in-patient or residential settings. Even in people's own homes staff intrude on moments of connecting, which can precipitate disconnecting:

The physical warmth and intimacy that usually revives and sustains husband and wife ... is all but smothered by the daily necessary morning and evening visitations by our splendid carers.

(Brock 2004:258)

The lack of privacy and staff intrusion described in these different settings is a barrier to connecting. Participants in this study experienced disconnecting through lack of privacy, which can further compound any disconnecting experienced in the coupled relationship itself.

Disconnecting through becoming

While many participants were acutely aware of their limited remaining time together as a couple, some participants also understood that their response to living with a life-limiting illness imposed 'difference' within the coupled relationship. This was experienced as disconnecting through becoming a 'patient', becoming a 'carer', and becoming a 'different person'.

Disconnecting through becoming a different person

Some participants experienced disconnecting through their partner becoming a 'different' person. Katy described a change in the way her husband behaved towards her that symbolised this:

He used to go past me and just smack my bum or something like that, or maybe grope. It just made me: I don't want that, that's not what I want. He was joking, but it wasn't a joke to me because I wanted to be loved. And all he could do was smack me on the bum.

Previously when Katy's husband did this "it was funny". Since he had become ill, this act had taken on new meaning for her; it no longer symbolised connecting because Katy no longer saw it as an expression of love. It is feasible that her husband's brain tumour is implicated here, as sexual disinhibition is associated with cognitive impairment (Wallace

and Safer 2009). With challenging behaviour, it can be easy to 'lose sight' of the person (Janes and Shirley 2008); Katy described a change not only in her husband's behaviour, but also in how she responded to him:

If I was single, I wouldn't go out and fancy him, like how I used to ... as he is now, I wouldn't go out and think, ooh look he's a nice bloke, he just wasn't my type. And unfortunately, I know he's my husband, but the feelings have changed ... I felt like I was kissing a stranger. I just felt, I knew he wasn't cleaning his teeth a lot, so I was just put off. But if I did, I'd be, it sounds really awful, but I'd hold my breath and it was just a quick peck and quick getaway, which sounds awful. It wasn't Jake, I don't know what else to say, it just wasn't Jake.

Katy no longer saw her husband as the man she married. His lack of personal hygiene, change in appearance and behaviour all contributed to him being "a stranger". Katy experienced disconnecting through her husband becoming a different person to the husband she once loved; "it wasn't Jake".

My intention is not to suggest that disconnecting is inevitable when someone has a brain tumour. Indeed, another partner in similar circumstances described her husband's personality as "emerging"⁵⁴. However, it is through presence and absence, connecting and disconnecting, that meaning becomes apparent. 'Disconnecting through becoming a different person' is just one facet of the prism of people's experiences.

Disconnecting through becoming a patient

Some of the participants described disconnecting from their partner through becoming a patient. This was not necessarily a matter of dependence, as the term 'patient' might suggest. What participants described is a change to their coupled relationship which took the patient along a different path to their partner:

[My husband] and I don't talk in great depth about our sexual relationship ... as the time has gone on we've grown more apart in that way, because in a funny way we've taken on a role of a carer and a patient, which isn't the same. It has these different little nuances than how things were before ... he doesn't understand my

⁵⁴ The re-connecting that Frances experienced in the light of her husband's "emerging" personality is discussed in the next chapter.

frustrations at times and these are things that can well up between us that means then our relationship isn't as close in one way, and in another it's almost too close.

Because Rita was unable to go out independently, she spent much more time with her husband than before:

I think what is a bit of the problem is I do find the fact that we are in each other's pocket all day every day ... I think what it is, is that I bring no stimulus to the day because I don't go off on my own to do something ... he goes off and does his thing with his work, and has something different to come back and tell me, but I don't go off to have any, so I'm beginning to sort of close down.

Without a life of her own, Rita was unable to contribute to the relationship as she once had and was beginning to "close down"; she was becoming "a patient" and was disconnecting from her husband.

Nancy understood disconnecting through becoming a patient in terms of withdrawing from her husband:

Nancy I think I've withdrawn a little bit away from, sort of the emotion and closeness really, as a result of it [MND]. I think it's almost providing a sort of protective sort of layer between him and me, and it's come from me, so therefore I'm not necessarily sort of sharing things quite as much, or doing things quite as much ...

BT A protective layer, so protecting?

Nancy Sort of distancing, taking a step back really, so that you're not quite so, so close really, emotionally. That as you sort of get increasing disability it's sort of easier to cope with in a sense ... it's sort of almost putting a slight distance, and there's also an urgency, it's very odd really because I know I've got quite a long time ahead of me but there's a sort of urgency to do things while I can, which means that if I want to do something, I need to do it now and not waste time doing other things ... I want to sort of concentrate on getting as much done and utilising whatever the skill is that I'm losing now because next year I might not be able to do it ... but that means that I'm withdrawing in a sense from family because I'm too busy doing ...

BT Have your priorities shifted?

Nancy I thought that family and friends were sort of, well they are number one priority, there's no doubt about, it but I'm sensing that within me things are driving me to do things that aren't necessarily related to family or friends.

Nancy described shifting priorities that separated her from her husband. She was aware that when she did not share her thoughts or concerns with him about her illness, and how it might present in the future, this was a means of protecting them both, and was experienced as withdrawing. Her husband did not always share her urgency to do things while she could, which resulted in her prioritising activities that were not necessarily shared ones.

Disconnecting through becoming a patient highlights the different journeys that patients and their partners take as they experience life-limiting illness. None of the patients in this study discussed what it was like to receive intimate care from their partner, which White (2003) explained can create tension. She presented the experiences of a woman with cancer who explained what it was like to be showered by her husband:

He used to undress me in a sexual way; now it is like I am a child. I hate every minute of it.

(White 2003:255)

This woman mourned the loss of sexual intimacy in their relationship. Only when her husband recognised this effect and nurses took over showering was the husband able to re-establish his role as a partner and lover.

Because none of the participants in this study described disconnecting through becoming a patient in this way, does not necessarily mean that they have not experienced this. In the limited time that I spent with them, the experiences they shared only provide a snapshot into their lives. What they did share, however, was their understanding of 'closing down' and 'withdrawing' that separated them from their partner.

Being-in-the-world is experienced through interrelated "systems of meaningfulness" (Sembera 2007:37). Given that 'patient' participants experienced disconnecting from their partner through becoming a patient, it is unsurprising that disconnecting through becoming a carer was also experienced.

Disconnecting through becoming a carer

The partners in this study who provided personal care⁵⁵ described a stark contrast between this form of touch and connecting as a couple. This was explained by Stella, when I asked if touch was important to her:

Stella I love my cuddles, you know, my children they cuddle me. My youngest is 30, had lunch with us the other day and we sat on the sofa and she actually came and cuddled me (voice trembles), it was absolutely gorgeous.

BT Lovely. And is that something you and [your husband] are able to do?

Stella No. Obviously I touch him quite a lot because I cut his hair and his beard and his nails and, you know, wash him and everything, do his teeth. No, no nothing like that.

Stella described the many ways that she touched her husband in the course of caring for him, but these were far removed from the cuddle she received from her daughter. Like other partners who did not receive hugs from their spouse, Stella relished close physical contact with family and friends. Although Webster and Heath (2002:223) have suggested that people with chronic illness or disabilities might be “touch starved”, it would appear that partners also experienced this in their disconnecting through becoming a carer.

Healthcare texts suggest that when partners assume the caring role and take on personal care, that this impedes a couple’s sexual relationship (Gallagher and Monroe 2006; Schover 1991; White 2003). Indeed, Hawkins et al’s (2009) qualitative study provided evidence for this. However, this did not appear to be the case for Claire, who had readily adapted to taking on the active role in her sexual relationship with her husband. Despite tending to all of his physical needs (washing, toileting and feeding him), Claire did not consider herself a carer, saying “I’m not his carer; I’m his wife”:

Claire No, I don’t mind the toilet bit and it’s not an issue, it doesn’t cloud me in any other way (long pause).

BT It doesn’t cloud you in your sexual relationship?

Claire No, it doesn’t, no. You know, I don’t think of that at any other point during the day or anything; that has never bothered me. I can imagine that some

⁵⁵ ‘Personal care’ includes washing, toileting, dressing and feeding another person because they are no longer able to do this for themselves.

people would find it really strange to be that personal with someone and then try and be intimate with them at the same time, but no, that doesn't bother me at all.

In contrast, Betty described how the caring activities she performed for her husband impeded their intimate relationship:

I remember the first MND meeting I went to, a lady said there I am not a carer, I'm a wife who happens to care for a husband with MND. And I thought afterwards, or sometime later, 'I wonder if she's changed her mind about that?' Because, okay you're too right at the beginning to say your life is just the same and you're looking after your husband as you would be, just more so, but there comes a point when it is different because they depend on you for absolutely everything, and there's things you wouldn't necessarily think of as being part of your normal married life. Wanting me to take his dentures out and clean them, clean him up when he's made a mess and (pause). That's when you feel that you are a carer, or I do. And I have to kind of switch off because it's too painful to think of what's happened to your husband if you're still thinking of him as your husband, your lover, your friend. It's a, I don't know, for me, there's a sort of cut-off point, it's just different ... and sometimes [he] will say, you know when he's on the loo or something, 'kiss me' and I can't, I don't want to at that time. It's, you know, for me that's really a different sort of thing, I can't, I find it hard, so I think that's what I feel about carers ... Sometimes I try to help [him] and I can't do it very well because I'm not strong enough and he's, you know, just trying to get him into position, and I just end up crying because it's such a sad situation for [him] and for me. We're both in places we don't want to be ... At the beginning it wasn't so bad, you're thinking, oh this is okay, we can still go out and do things. But as it is now, [he]'s just a prisoner in his body. And I'm there with him.

Both Betty and her husband were trapped; her husband was "a prisoner in his own body" and Betty was incarcerated alongside him. She was trapped in her caring role and found little joy in her current life:

The only joy really is mainly the past. I think, you know, looking at old videos and photos and you go back in your life (sobbing); and then you wake up (pause). You

get lost in the past, and that's lovely, and then you wake up and you're here and now...

When Betty said, "I feel that I've become a carer and not a lover anymore", she described the intrusion of personal care on their intimate relationship. Research has shown that both men (Gilbert et al 2009) and women (Gilbert et al 2009; Hawkins et al 2009) caring for their partners have re-positioned their sick partner as a child, resulting in them no longer being seen as a sexual being. However, Betty did not seem to be saying that she perceived Jim differently, but that the caring activities that she performed for him stood in the way of their connecting as a couple. It was not possible for her to be a carer and a wife in the same moment. When providing personal care, Betty 'switched off' from thinking of him as her husband or lover and, in these moments, experienced disconnecting through becoming a carer.

In contrast, Michael saw his caring role as a privileged position:

Caring is not a chore, it's a privilege ... it's a privilege to be in a position to care for somebody and the fact that this somebody is my wife, and of course we've always been caring for each other for 38 years. So it is a continuation in a different form of what one's been doing ... because I am caring for the person I love, that makes it a privilege.

The "privilege" that Michael described might have been feasible because, at the time of the interviews, his wife was relatively independent and Michael did not need to provide any personal care. The 'care' that Michael provided included supporting his wife with the washing and shopping, getting the shower ready for her, and becoming the sole driver.

Heidegger (1962:158) used the word 'solicitude' [*Fürsorge*] to describe caring for another:

... solicitude has two extreme possibilities. It can, as it were, take away 'care' from the Other and put itself in his position in concern: it can *leap in* for him. This kind of solicitude takes over for the Other that which he is to concern himself. The Other is thus thrown out of his own position ... In such solicitude the Other can become one who is dominated and dependent, even if this domination is a tacit one and remains hidden from him ... In contrast to this, there is also the possibility of a kind of solicitude which does not so much leap in for the Other as *leap ahead* of him [*ihm vorausspringt*] in his existentiell (*sic*) potentiality-for-Being, not in order to take

away his 'care' but rather to give it back to him authentically as such for the first time.

(Heidegger 1962:158-159. Italics in original)

The solicitude that Michael described was 'leap ahead caring', which enabled his wife to care for herself. In contrast, Betty's solicitude was directed towards doing what her husband could no longer do for himself; she provided 'leap in caring'. By taking over his care from him, Betty's husband was displaced ~ "thrown out of his own position" (Heidegger 1962:158) as her lover ~ and Betty experienced disconnecting through becoming a carer. This leaves me wondering whether Michael's perception would change if his caring role extended to personal care. If he was required to provide 'leap in caring', might he also experience disconnecting through becoming a carer? A longitudinal study might be able to answer some of these questions.

I am also puzzled by the differences between Betty and Claire. Both of them provided personal care for their immobile husbands that included intimate tasks such as toileting. Yet Betty seemed to be describing moments of disconnecting through becoming a carer, whereas Claire did not perceive herself as a carer. Perhaps the difference can be explained by considering whether their relationships remained egalitarian. Indeed, Esmail et al (2010) found that when partners take on the caring role and people with disabilities assume a dependent, care-receiver role, the equality in couples' relationships diminishes and this imbalance can impact upon their sexual relationship.

Carolyn Ellis (1995:115) wrote in her journal:

It's harder and harder to talk to you [her dying partner] about my feelings. The sicker you get, the more I don't want to place the burden of my pain on you. And the less I think you can handle.

From this description, it would seem that 'leap in' caring is not merely a matter of performing physical care, but involves couples moving from a position of mutual equality to one of 'carer' and 'cared for' in their emotional relationship. This was exemplified in an interview with Betty:

I cry on my own. I do cry in front of [my husband] ... I don't like to though, because it upsets him and he should not see me crying. But, we've always had a very open

relationship ... if you can't discuss and talk about things, you have no marriage.

You have to talk about things and you have to say the truth even if it's hurtful.

Betty had considered their marriage to be open, without secrets. Yet now that her husband was ill and dying, she protected him from her true feelings. She tried not to cry in front of him if she could help it in order to protect him, and also recognised that "if you can't discuss and talk about things, you have no marriage". The intimacy that they had once shared as a couple was being subjugated to illness, and the mutuality that constituted connecting was fading. This was further exemplified by Ellis (1995):

Occasionally, we have a close moment when we aren't consumed by the illness.

(Ellis 1995:157)

As I take care of Gene, sometimes I feel love, but mostly I am an efficient robot.

(Ellis 1995:218)

For Betty, there was little joy left in the life she shared with her husband:

Betty It is just hard to do things that give pleasure to both of us ... each time there's pleasure there seems to be some problem that goes with it.

BT Does that mean the pleasure suddenly stops when there's a problem?

Betty I suppose it does in a way because you go back into sort of carer mode, you know, it's just a switch.

Even in moments of mutual pleasure, illness intruded and Betty switched back into "carer mode". This was in sharp contrast to Claire, whose husband was equally immobile and physically dependent, but was not ill. She and her husband were still able to go abroad on holiday together and had adapted to a life where she 'became' his hands and legs.

Despite Claire's assertion that she was "not his carer", there were moments when their sexual relationship was not an egalitarian one. Claire explained that her husband's breathing was impaired, and he was unable to lie in bed without non-invasive ventilation. This required him to wear a mask, tightly secured over his mouth, which was connected to a machine that forced air into his lungs. It was not the ventilator itself that distracted Claire (she said this was very quiet), but her husband sometimes needed rolling onto his side during sex and they had to pause until his breathing came back to normal:

Sometimes he'll say, 'roll me over', and it's like a passion killer ... I've got to put him on his side until his breathing comes back to normal.

Even with this mask, her husband had difficulty lying flat for sex. This had shortened their love-making sessions and posed restrictions for Claire:

He struggles because he can't breathe laid down, so you've got to kind of be a bit more flexible and, quick ... I think it does kind of restrict me. I am more sort of aware of him more than I am of me.

Claire explained that, because of the reduced frequency of intercourse, her husband tended to reach orgasm before she did. However, she recognised that this was not the only reason for the reduced sexual satisfaction she experienced. When having sex, Claire was unable to completely relax:

It's still good and I know that he gets worried and he's like you know, 'is everything alright?' sort of thing and it's fine, you know, it's perfectly alright, perfectly fine, it's great ... But at the back of my mind I'm sort of, you know, 'are you okay?'... He's worried about his performance and I'm worried about him.

Even though Claire and her husband both described their sex life as "great", their differing concerns revealed moments of disconnecting:

He's looking at it from the sex point of view and I'm looking at it from the health point of view.

(Claire)

Claire worried about whether her husband was in pain, or if his breathing was impaired, and this made it hard for her to relax and enjoy sex. Even though Claire did not describe herself as a carer, in moments when she was more aware of her partner than herself, she also experienced disconnecting through becoming a carer.

In summary, it was not the need to provide physical care *per se* that brought about disconnecting through becoming a carer. When illness created an increase in dependency, connecting was displaced by 'leap in' caring. The loss of equality and mutuality in caring for the other showed itself as a need to cushion and protect the partner, and moments of mutual joy were subsumed by illness.

Disconnecting in the shadow of impending death

Although all participants were aware of the life-limiting nature of the patient's illness, humans do not live authentically all the time (Heidegger 1962). For some of these couples living with a life-limiting illness, the certainty of death, and the separation it brought was announced during intimate moments. Michelle had described sex as "a big part of our relationship", but this changed as she and her partner lived in the shadow of impending death:

He still wanted me to kind of do things [oral sex and masturbation] to him, which I did do some things to him, probably right up until a couple of weeks before he died, you know, because I knew that he needed that. But the whole sex thing [intercourse], we couldn't, I think we tried to have sex; I just got on him because he wanted to feel it again and I think it was only a few months before he died but it just upset me too much. I kind of did what I had to do and got upset, and that upset him as well, but I think it was because he thought I didn't fancy him anymore. And I kept trying to say to him it's nothing to do with not fancying you Dave, it's just the whole (pause). It's sad, you know, I want to be held, I don't want to just kind of, I felt as though I was violating him almost ... Because he couldn't move. So to have sex, the only way we could have sex was obviously for me to get on top of him but he wouldn't be able to do anything, you know, so I would have to do every, you know, the whole, it just felt, it didn't feel right ... it just didn't feel like sex, it didn't feel like, you know, like it should and it just upset me, I think because for me it kind of brought it ever more closer that he was dying and I was going to lose him soon, you know, and I was never going to have sex with him.

It "didn't feel like sex" when Michelle's husband was unable to move because, for her, sex was a reciprocal activity, one of connecting through mutual exchange. Even though she was able to masturbate her husband and give him oral sex "until a couple of weeks before he died", she was unable to have sexual intercourse because it created an environment in which something showed itself:

He always used to say, when we had these heated discussions about having sex and things, I would say to him, 'Dave, if I was like you, if I was completely immobile, you wouldn't be able to have sex with me and just lie on me without me moving an inch of my body'. And he was like, 'yes I would, yes I would'. 'No you

wouldn't'. It would be like sleeping with someone that looks like a corpse ... But he was like, 'no I would, I would'.

Michelle wanted to "be held" but her husband was unable to move his arms. It was during sexual intercourse with his immobile body that the reality of his impending death was brought home to Michelle. She realised that she "was never going to get that proper sex again with Dave" and his passive body showed itself as a corpse.

Davis (2005) described the disabled body as a threat because it reminds the person of their own fragility. However, what Michelle has shown, is that the disabled, passive body can be a threat to the partner, reminding them of the fragility of their life together.

The disabled body generates anxiety because it is always the reminder of the whole body about to come apart at the seams.

(Fraser and Greco 2005:147)

What Michelle has shown is that the body of the dying person can generate anxiety because it reminds the couple that it too is "about to come apart at the seams":

The feeling that having sex brought me was just a constant reminder that I was going to lose that person soon ... obviously I didn't want to upset him by saying that, because it was like reminding him, you know, you're dying.

Death is present to us if it shapes the meanings of situations we find ourselves in (Wrathall 2005). Ellis (1995) described how her and her dying partner's "bodies and souls" united during sex. Agony merged with ecstasy during sex as orgasm brought with it a "wave of pain" (Ellis 1995:125) that engulfed her. She described orgasm as:

A beautiful, yet agonising and unprotected moment. The pain and ecstasy, intertwined in the same knot, exploded in sex.

(Ellis 1995:126)

In the ecstasy of orgasm, Ellis' sense of impending loss was heightened. Like Michelle, she was reminded of her husband's dying. It was through sexual union that their impending separation through death was brought into awareness.

Sexuality and intimacy as silent bedfellows

“Most sexual behaviour is accompanied by a great deal of silence” (Gagnon and Simon 2005:77). In this study, the silence surrounding sexuality and intimacy became apparent in the reply slips from those who did not want to take part in this study. As one woman explained:

Most people of our age don't discuss this with their partner.

This woman assumed that silence was common to others of her age group (61-70 years). However, this study has shown that, regardless of their age, these couples living in twilight experienced disconnecting through silence. This silence created opportunities for 'disconnecting as misunderstanding' and 'disconnecting as pretending'.

Disconnecting as misunderstanding

As people become frailer, the verbal expression of feelings becomes increasingly important (Cooper and Guillebaud 1999) because couples are no longer able to connect physically. However, many couples have limited experience of talking about sexual matters (Gagnon and Simon 2005). This was highlighted by Michelle, who explained that she did not know how to express her feelings about having intercourse with her partner:

I didn't have the words to say what I meant, but I think he thought that I just didn't fancy him anymore and, you know, 'why don't you want to do this? Why don't you, I can still', you know, 'you can still get on it and please yourself'. I think he still wanted to think that he could please me, whereas for me it wasn't like that, I didn't need to have sex to be, feel loved or needed by Dave and I guess I wasn't really explaining myself. I think maybe I used to try and shrug it off, the conversation, I wouldn't really address it because we'd never talked, you know, no-one had ever talked to me about it.

In her bereavement, Michelle was troubled by the arguments she used to have with her partner about sex. She didn't have the words to explain what she felt to him, and none of the professionals had ever spoken with her about this aspect of their lives. Sexuality and intimacy remained silent bedfellows, and Michelle and her partner experienced disconnecting as misunderstanding.

For others, a reduction in sexual contact arises when partners initiate sex less often to avoid making demands on the ill person (Cooper and Guillebaud 1999; Leiber et al 1976). As Nick explained:

These days I tend to leave the timing [of sex] to her so, otherwise, you know, there's no point if she's overly tired or (pause) flogging a dead horse, as they say (laughs) ... I probably, eight or nine times out of 10, leave it to her ... as I said, there's no point in flogging a dead horse, so I just don't bother if she's not, if I don't think she's going to be interested.

Nick's use of metaphor probably reflected his embarrassment in talking about this with me, rather than a lack of sensitivity for his wife's well-being. He had previously described her increasing tiredness, and did not want to make demands on her, saying:

It makes it much more pleasurable if you're both enjoying it.

When interviewed, Nick's wife attributed the reduction in sexual frequency to her own tiredness. For others, however, there is a potential for misunderstanding:

Because you're not initiating it, she thinks 'he doesn't love me anymore'.

(White 2003:255)

The silence surrounding sex provides room for misunderstandings to flourish, and for people to experience disconnecting as misunderstanding. Rita described how she had interpreted, and re-interpreted the reduced frequency of their sexual relationship:

I think what helped me enormously was that ... he had been put on tablets ... and I hadn't realised until about a year afterwards, or more, that they had side effects of decreasing your libido. And that actually was a help to me to know that ... rather than maybe just my body falling to pieces, you know, and that gave me a little bit more confidence. Rather than feeling it's just difficult for him to cope with my physical appearance ... And I think I was blaming myself for perhaps a year and a half to two years, maybe, thinking that it was me ... and I don't think maybe that's quite the case ... it wasn't all my fault that he was less interested. That if these drugs were doing that, then that was part of it, and that has made it much easier for me to accept, he doesn't feel like it either so that's great. It's not just me ... it wasn't just me turning him off.

Rita had believed that her husband had been initiating sex less often because he found her less attractive. She recognised that the silence surrounding their sexual relationship had compounded the disconnecting she experienced:

I hadn't ever read the bits of bump that came with the tablets a year before, because it would've helped, as opposed to taking it on and not really discussing it and thinking it was all my doing.

Rita only re-interpreted her husband's altered sexual interest once they had spoken⁵⁶. When sexuality and intimacy remain silent bedfellows, there is a potential for disconnecting as misunderstanding.

Disconnecting as pretending

Carolyn Ellis (1995) described the effect of her dying partner's oxygen tubing during intimate moments:

A loving embrace often ended up with both of us strangled by the hose.

(Ellis 1995:61)

Ever mindful of the oxygen tubing, they were able to manage its intrusion through mutual laughter, referring to it as "the python" (Ellis 1995:61). However, Ellis worried that she would have difficulty feeling sexually aroused, and felt unable to share her worries with her partner. She described managing this by closing her eyes to avoid seeing the tubing during sex.

For others, the reality of their situation cannot be erased by closing their eyes. In order to achieve sexual fulfilment, Claire needed to believe that her husband would not die during sex:

We joke and I say 'what do I say to your mother if you died during sex?' How do I explain that one?

Although this was something that Claire did joke about with her husband, her fear that he would die during sex intruded upon their sexual relationship:

⁵⁶ This conversation was prompted by her husband's concern at receiving tablets in an unusual packet. This prompted him to read the leaflet (in Rita's presence), and they both discovered that his medication caused a reduction in libido.

BT You said that at times it's not as satisfying for you. At those times, do you sometimes pretend that it's okay?

Claire I have done, yes.

BT And had you before he got MND?

Claire Very occasionally.

BT Perhaps you pretend a little bit more now, is that what you're saying?

Claire ... sometimes you just have to ... because his body's packing up I don't want him to feel that he can't satisfy me.

In these moments of 'leap in' caring (Heidegger 1962), when she feigned sexual satisfaction, Claire's intention was to shield her husband from the enormity of his situation; that his body was failing him further and he was not always able to please her sexually.

Esmail et al (2010) found that female partners of men with MS also preferred to hide their lack of sexual pleasure, valuing their partner's sexual satisfaction as more important than their own. This is not a practice exclusive to partners, as women with MS also preferred to forego their own sexual pleasure in order that their partner believed that they were sexually satisfied (Esmail et al 2007). It is unclear whether this pretence is something that only women do, as this was not a question that I asked any other participants, and was not volunteered in any of the other conversations.

It is feasible that pretending to be sexually satisfied could become "an invisible wall that separates her from her partner" (Masters and Johnson 1970:242). The 'cost' to Claire, for her husband's 'gain', could potentially become a cumulative cost that results in her initiating sexual contact less frequently. As MND had rendered her the dominant partner sexually, this could result in a further reduction in the frequency of connecting through sex.

In moments of pretending, the mutuality of connecting that normally defined their sexual relationship was missing. Claire's pretence disrupted intimacy as "ignorance of the truth separates them further" (Masters and Johnson 1970:248). In these moments of disconnecting, Claire perhaps 'became' the carer and rendered her husband 'the patient'.

Conclusion

“Humans exist in a world of relationships” (Mackey 2005:181), and dying brings with it separation. This study has shown that, in the being-in-the-world of coupled relationships, this separation begins before death through the experience of disconnecting.

Other research has found that, in couples where sexual intercourse has ceased, non-sexual touch decreases and even stops altogether because of the belief that it will lead to sex (Gilbert et al 2009; Hughes 2000; Hughes 1997). However, this study has shown that these couples living in twilight experienced disconnecting even when sexual relationships continued. The theme of disconnecting was experienced through a lack of reciprocity in touch as well as diminished sexual contact.

In experiencing sexuality and intimacy as disconnecting, the mutuality that had hitherto been expressed (through touch, the sexual relationship and shared activities) became subsumed by illness. The disease, one’s historicity, disfigurement, lack of privacy and the equipment provided were all barriers to connecting. Sexual behaviour created an environment in which disconnecting showed itself: this ranged from the imperfect, incomplete body to a lack of intimacy and mutuality within a relationship and, for some, the immediacy of impending death.

For many participants in this study, experiences of disconnecting were not static; they were often experienced alongside moments of connecting. For some couples, differences and misunderstandings become exacerbated, and experiences of disconnecting began to outweigh their experiences of connecting. Loss carries significance “in light of the meaning that this experience has in the lives of those experiencing it” (Parsons-Suhl et al 2008:39).

Chapter 7: Being-towards-death as re-connecting

Introduction

The previous chapter explored the theme of disconnecting that many of the participants in this study experienced in their sexual and intimate relationships. Readers of this work might question whether I have focussed on “deficits and disabilities ... while the possibilities of living with [life-limiting] illness recede?” (Ironsides et al 2003:181). However, it is through revealing disconnecting, that I became aware of the potential for re-connecting. Having described their experiences of disconnecting, some participants were keen to redress the balance and describe the positive experiences in their life. As Frances explained:

Situations like this I think uncover long wounds that have grown up, but they also can be very healing in some aspects of this. I wouldn't say it's all negative.

Like Frances, some of the participants described ‘re-connecting’ with their partner after a period of disconnecting. For re-connecting to take place, connecting and disconnecting are always already there. This chapter discusses the theme of re-connecting that some couples experienced in their limited time remaining as a couple, in their being-towards-death.

Re-connecting in the shadow of impending death

The basic human structure of ‘living-into-possibility’ is central to Heidegger’s (1962) discussion of what it is to be human (Johnson 2000).

Because the essence of human being is finite, it is never complete, finished or done. It is always in a process of ‘becoming’.

(Johnson 2000:139)

When someone is living with a life-limiting illness, there are occasions when they become acutely aware of the finitude of their existence. In what Heidegger (1962) called ‘authentic mode’, they are explicitly aware of their own mortality. Not in the way we might say, ‘I could get run over by a bus tomorrow’, because we carry on our lives in the belief that we will not be killed by a bus tomorrow.

It is through the act of understanding the nearness of possibility of one's own death that new possibilities for being emerge.

(Gullickson 1993:1388)

For some of these couples living with a life-limiting diagnosis, the certainty of death and separation was brought home to them during intimate moments and this awareness of their future effected change in the present. For Tom, who had experienced an unsatisfying sexual life with his wife for many years, the week just after his diagnosis precipitated an intensity to their love-making that brought him and his wife together in a way they had not experienced for many years:

We went through that really good period, through that really horrible period, when I first had this diagnosed. That was probably one of the strongest periods of our sexual relationship because it just seemed to be something that both of us wanted anytime of night, anytime that it was right. It just seemed to be a relief for the two of us and it worked and it just came, I mean it was really a strengthening of our relationship from that point of view.

In their moments of "re-loving", Tom felt that he and his wife "went from nothing" to a mutuality in their love-making that had not been present for over 20 years:

... whether that was just an outgoing of each other's emotions and just wanting to be, I don't know, sharing something together, I don't know, but it was strange, it was something that, it was a one-off.

The shadow of Tom's impending death brought with it possibilities of repair that were realised for that week alone. In recognising its being-towards-death, Dasein becomes aware of possibilities for being-in-the-world-with-another (Heidegger 1962). For Tom, these possibilities of being with his wife were unsustainable; they were "a one-off".

Even though the experiences of re-connecting with his wife (through sexual reunion) did not continue beyond that week, Tom described it bringing about a momentary "strengthening" of their relationship. It is unclear why these moments of re-connecting only lasted for a week, though it is likely that the difficulties in their sexual relationship were complex and deep-rooted. It is also likely that the "relief" that Tom spoke of could not be sustained because Dasein lives *into* possibilities (Heidegger 1962). When Tom was told that he had MND and that this was a life-limiting diagnosis, this created a moment of

disruption (*Angst*), releasing Dasein from its fixed habits (Heidegger 1962). There are only moments where we are able to orient our lives towards death because the moment-by-moment experiences of life intrude, thereby foreclosing Dasein's horizon of possibilities.

Like Tom's experience with his wife, Susie also spoke of an increased intensity to her sexual relationship with her husband immediately after she was diagnosed:

Susie It was an intensity of you've only got one life, live it. Stop worrying about being tired, stop worrying about the children. Just concentrate on how much you love this man.

BT Uh-uh (pause). And connecting⁵⁷ emotionally?

Susie Absolutely, because I'd been connecting at maybe 50%, because the 50% was thinking about [the children] ... But it was weird that our intensity, um, really did go a bit mad. We just needed to hold each other really, really close. But it's not that surprising.

BT What triggered that do you think?

Susie Uh, this was a very big, this was a big thing that was happening. And that maybe we wouldn't be, have a chance to be intimate for a while and that we needed to just remind each other how much we meant to each other. It was our way of expressing how much we meant to each other.

For Susie, like Tom, this intensity was provoked by the threat of separation and loss. Bowlby's (1979) theory of attachment suggests that threat of loss arouses anxiety, which is mediated by "an urge towards proximity" (Bowlby 1988:121):

Any situation that seems to be endangering the bond elicits action designed to preserve it, and the greater the danger of loss appears to be the more intense and varied are the actions elicited to prevent it.

(Bowlby 1985:42)

In the shadow of impending death, both Susie and Tom faced permanent separation from their partners. They sought haven through re-connecting as the bond that united them was in jeopardy; they clung to each other for reassurance (Bowlby 1985).

⁵⁷ In using the word 'connecting', I was beginning to test my interpretations.

Threat to the continued accessibility of the attachment figure gives rise to protest and to active attempts to ward off the separation.

(Weiss 1991:66)

Perhaps 'hanging on to life' was a protest against impending separation through death. The 'two-as-one' nature of connecting through sexual intercourse united these couples, and thereby momentarily sheltered them from the separation that would inevitably result when one partner died.

Susie also described connecting with her husband in the shadow of her impending death and the uncertainty of when they would be able to be intimate again. She recognised that she had previously been preoccupied caring for her children and felt that she was letting her husband down by her reduced sex drive (which she attributed to chemotherapy). When her husband was away, Susie's life revolved around hospital appointments, chemotherapy and caring for her children. She became "Susie with cancer", invisible as a person, and did not need to worry about her loss of libido.

When her husband came home, it felt like they were "going on a date" and she made a special effort to connect with him. Susie was unsure when they would be able to be sexually intimate again and described needing to "hold each other really, really close". During this fortnight, she rediscovered her identity as a woman and a wife, and experienced re-connecting with her husband:

The children are an incredibly huge distraction ... You do want to put your heart and soul into them, and relationships with your other half can really take a back seat. You can feel exhausted and you can still make love with your partner, but not be emotionally connected because you're so tired. And nowadays it's a case of well hang on, let's get on with it when the kids are at school rather than do something else. He's immensely important to me and I'm immensely important to him, so let's celebrate that ... and he knows that after nine o'clock you can't get a sentence out of me, I'm so tired.

It was during these moments towards authenticity (in the shadow of their impending death) that Tom and Susie both experienced re-connecting with their partners. They both recognised that they had previously had sex before without fully connecting, whereas in the shadow of impending death they experienced moments of re-connecting.

The authentic self does not merely recognise the significance of being and passively await its death; it anticipates it (Gelven 1989). “Death becomes a constitutive part of being” (Gullickson 1993:1389) and opens up possibilities for being (Heidegger 1962). This was eloquently expressed by Philip Gould (2011) after being told he had three months to live when his cancer recurred:

Suddenly life screams at you in its intensity ... My life became death. It regained a quality it didn't have before. It entered a new zone.

When death becomes part of being, it creates new possibilities for meaning as people take stock and re-evaluate what is important in their lives. As Susie and Tom have shown, it creates new possibilities for “living today” (Gullickson 1993:1390) through re-connecting in the shadow of impending death.

Being-towards-death provides possibilities for re-connecting

It was not only the person who was dying that interpreted their relationship in the shadow of impending death; being a partner of someone who is dying can alter interpretations too. For some people, such as Stella, her husband's terminal diagnosis brought with it hope that their relationship would change:

Now that he knows he's got another 10 years he might actually try and live life instead of, you know, concentrating on himself in front of his computer, which he now can't use very well ... I mean there are masses of places that are wheelchair friendly ... maybe we'll have a life again. It's been quite difficult not having a life together really, you know to be so separate. But maybe things would improve if we could share stuff together again.

Stella spoke of having lived “separate lives” with her husband. They no longer went on holiday or out for meals together (since her husband needed feeding), and their sexual life had stopped. Stella described her husband as being preoccupied in his study, and she socialised with friends alone. They had recently been told that his MND was of the slower, progressive type, and Stella believed that her husband might have 10 more years to live. While daunted by the prospect of him needing long-term care, and the financial burden of this, she was hopeful that they might re-connect as a couple.

Stella's understanding can be understood in the threefold structure of Dasein's temporality; "informed by what has been and influenced by what is to come" (Smythe 2011:36). Her hope was founded upon knowing that there might be sufficient time remaining for them to establish a life together again, and might have been founded on the old adage⁵⁸, 'time heals all wounds'.

However, it is through our "living into possibility" that meaning is construed (Heidegger 1962:138). Stella did not describe any basis for this hope of re-connecting with her husband, and I do not know whether it was realised. Possibilities for re-connecting in their life as a couple 'alongside' each other might have needed more than the knowledge that his death was more distant.

Unlike Stella, Frances was aware that her husband's life was very limited; she spoke of him having already lived longer than the predicted three months. She also spoke of an opportunity for re-connecting, because living in the shadow of her husband's impending death had brought with it a reframing of her understanding of their marriage:

Having said that I was thinking of going [leaving her husband] in two or three years' time, I absolutely know that the minute I realised that there was something really wrong with him ... I knew this is where I had to be. I mean I've loved him so much, I've tried to love him, and I've failed to love him the way I wanted to love him, this is a chance for me to love him.

Frances explained that she had decided to leave her husband when her son was independent. However, when she knew that her husband was terminally ill, she saw that this provided an opportunity for them to be close in a way they had not achieved before. Her husband's illness and impending death provided new possibilities for loving him.

Since his terminal brain tumour was diagnosed, Frances also spoke of changes in her husband's behaviour, as well as changes in the way that she responded to him:

Frances It's made him a lot more talkative than he ever was, he's talked to me more in the last six months than he has in the previous 31 years. Um, secondly he's extremely forgetful. So I'll tell him something six or seven

⁵⁸ From *Troilus and Criseyde*: "As tyme hem hurt, a tyme doth hem cure" (Chaucer 1385:173, vs.350).

times and he still will ask me again, and before he was diagnosed I got impatient with that, but now I'm extremely patient with it.

BT What's made that difference?

Frances Oh, because he's ill and he can't help it. Whereas before I thought he was just trying to wind me up, or hadn't listened or wasn't attending, that his notice of me was so low that he just didn't bother to remember. But now I know he can't remember because he's had that part of his brain removed, it's fine, I can take it.

Prior to his surgery, Frances had interpreted her husband's forgetfulness as a lack of concern and "notice" of her. She had since reframed her interpretation of his behaviour and now saw it as something that she could understand and forgive. Her husband's diagnosis brought with it opportunities for re-interpreting his behaviour and enabled re-connecting within their fragmented relationship:

Frances So I feel that this time is gifted time, since the operation, since the diagnosis ... I think this is positive time, not negative time.

BT You spoke about your son and Alistair re-connecting⁵⁹, is there an example of that with you and Alistair?

Frances Yes, two days after the operation I was sitting by his bed and I was finishing knitting a scarf for him that I'd been knitting for three years but never had time to finish ... and I put it round his neck thinking to myself, I wonder if he'll ever get out of here to wear it, and when I did that he said to me, 'you've been an absolute angel since I've been ill'. He's never been ill before, so I've never had the chance to love him the way I want to love him, and he's never let me love him the way I want to love him. He's never let me close before and he said, you know, 'you've been an absolute angel since I've been ill and I realise I haven't been very kind to you when you've been ill in the past and I'm sorry'. And that's very, very precious to me, because really he's been quite mean to me when I've been ill.

⁵⁹ The term 're-connecting' had not been used by Frances, but she had described an occasion when her husband and daughter re-established their relationship. I introduced this term as a way of testing out my interpretations.

BT And then recognising that now?

Frances Is fantastic, yeah. Because it's like it didn't, it didn't happen then.

Frances described her husband's limited life as "gifted time" because it provided an opportunity for her to love him in the way she wanted to: to be close to him. It also provided opportunities for him to review their relationship and to apologise for his lack of recognition of her and her needs. For Frances, this recognition from him now 'erased' the earlier pain: "it's like ... it didn't happen then". This enabled her to 'wipe the slate clean' and to see this time as "healing time":

Situations like this, I think, uncover long wounds that have grown up. But they also can be very healing in some aspects of this, I wouldn't say it's all negative ... I was talking about what a precious time this was for us together and how I got to spend some time with him at last, which is how I'd hoped the marriage would be right from the start and, you know, if this hadn't happened, we'd have gone on in the situation we were in and it would never, a lot of things would never have been resolved and they are being resolved and it's really positive and it's a gift.

When I asked how she wanted to be able to love her husband, Frances said, "I want to have conversation. I want to have engagement in what I'm doing". She explained that she and her husband had lived "next to each other" rather than "together" for many years:

Frances I'd like to have shared a lot more of the things with the boys, which we have done since he's been ill because he can't go anywhere without me and we've actually done things with them together, just little things, we went out to lunch with some friends on Sunday and our youngest son came with us and, you know, that was really nice, just the three of us to go out together, we've never done that. And I'd like to have done things like that, just live together, not next to each other ... The simple things like just, when he's in bed, lying in bed, which he does a lot of the time, just going up and lying next to him. He never had time to do that and never been comfortable with me near him, physically, so I couldn't believe it, a few months ago I was lying in bed next to him and this finger came out and actually touched me. And that's never happened before, never ever, he touched me because he wanted to

and, I would've loved to have been touched (Pause. Eyes fill with tears.)

BT So that was something very special.

Frances Yes. And now occasionally he puts his hand over and just rubs my back, a bit, and I've asked him to rub my back in the past and things but he's just not been comfortable doing it. Didn't want to do it. He'd sort of go like that (roughly pats the table, very briefly) and then stop immediately. So I mean it's all, it's everything really.

BT You spoke about it as a healing time.

Frances Yes, and that's another reason I'd call it that. It's too late for anything more serious [sex], if you see what I mean, but it's still good to know that he gets some comfort from touching me and I'd have liked to have offered him that comfort in the past but it's not something he's been able to accept.

Even though her husband was dying, and their time together as a couple was therefore limited, Frances recognised the value of the time that they were able to share. Now that he was ill, neither of them were working and there were opportunities for them to spend time together, and for them to be physically close. This enabled re-connecting for them as a family and as a couple. Because her husband was not considered well enough to take part in this study, it is unclear whether he re-interpreted his relationship with Frances in the context of his dying. Given that he now apologised for things that had taken place many years ago (and some of these were unprompted), it is feasible that it was not merely spending more time together that made re-connecting possible.

Frances did not envisage that there would be opportunities for re-connecting sexually, because Alistair wore incontinence pads in bed, and their sexual relationship for most of their married life had been "virtually non-existent". Instead, she valued her husband finally acknowledging her needs, being remorseful for previous hurt he had caused, and for reaching out to her physically and emotionally, through touch and apology. What Frances described as "healing time" contained both verbal and non-verbal healing actions, and thus presented opportunities for re-connecting:

... the rejection I've felt, I guess, is being healed.

In the second interview, Frances described one of the conversations she had with her husband that had been prompted by describing (and re-framing) her experiences in the first interview:

I hadn't thought about my mother for a long time, and I actually talked to Alistair about the effect she'd had on us. And we had a conversation about the fact that, um, he had never been keen on, after she moved in, on touching me and so on, and about our sex life. And he actually said, he actually admitted for the first time ever, 'yes it never really worked did it'. And that, for me, is a fantastic thing; that he's prepared to actually say that and admit that ... and I tried to talk to him many times before about this but he hasn't been open to it, but he is now.

Although Frances' mother only lived with them for five years, their sex life did not improve, and Frances described their sexual relationship as "disastrous" in the intervening 25 years. It had stopped completely several years before the research interview. Whenever Frances had previously attempted to talk with Alistair about this, he had "not been open" to discussing it. The conversation that she had with him after the first interview was therefore a significant change for Frances. Having described her marriage as a "compromise", the re-connecting that she described was of great significance to her. A 'fusion of horizons' (Koch 1996) occurred between Frances and her husband, as he heard her view of their sexual relationship and, seemingly for the first time, formed a new view of it himself. His apology enabled them to connect in a way that they had previously been unable to do. As a couple, they were in the process of becoming.

Conclusion

Experiences are neither static nor fixed (Heidegger 1962). In flux, they are constantly moving, shifting and flowing. For some couples living in the twilight of their years, the ebb and flow of connecting or disconnecting included moments of re-connecting. Some participants interpreted their being-in-the-world of their coupled relationship differently when they first became aware that their life was limited. Immediately after receiving the diagnosis, in moments of authenticity when 'in the shadow of impending death', some people described re-connecting sexually. Other participants, whose being-in-the-world as a couple had been to live somewhat separate lives, 'alongside' each other, described opportunities for re-connecting that were non-sexual.

Many participants in this study did not describe experiences of being-towards-death as re-connecting. I wonder whether others might also have realised new possibilities for being and experienced re-connecting as they journeyed towards the end of their coupled relationship. I also wonder whether healthcare professionals might have a role in facilitating re-connecting if possibilities for Being are recognised.

Chapter 8: Being-towards-death-of-the-couple

Introduction

When I first embarked on this study, my intention was to gain an understanding of the experiences of patients and partners of patients living with a life-limiting illness. However, their shared experience is not only shared by them as individuals, it is experienced by the couple as a unit. In these patients being-towards-death, I have come to understand that their coupled relationship is also dying.

When we live authentically, awareness of our dying creates possibilities for being (Heidegger 1962). For participants who experienced re-connecting within their coupled relationship, new possibilities for “living today” (Gullickson 1993:1390) were evident as impending death shaped their experiences. Similarly, those who found new ways of connecting when sex became difficult or impossible found new meaning in non-sexual touch. However, participants also spoke of death as a finite event which brings about an end to possibilities for their coupled relationship.

The constitutive pattern arising from this study, I have called ‘being-towards-death-of-the-couple’. In order to illuminate the meaning of this phenomenon, the following themes will first be explored: ‘an illness shared’, ‘time running out’, and ‘a widow-in-waiting’.

An illness shared

The tenets of holism suggest that illness not only impacts upon the person’s body, but also their emotional well-being and their social relationships (Dossey et al 2008). For the partner of someone who is diagnosed with a life-limiting illness, their life also changes irrevocably as they too construct and re-construct meaning in their experiences. This was explained by Michael:

We do everything together, so anything that happens to her happens to me, so to speak. I don’t have the disease or the physical disability but every action or activity has an impact on me ... so I always use the word ‘we’, I never use the word ‘I’ ... it is ‘we’ it is ‘us’ and it has had a dramatic effect on our life ... So it isn’t just [her] who’s been affected, we’ve both been affected.

Similarly, a partner of someone with multiple sclerosis said:

It was his diagnosis but it was our disease...

(Esmail et al 2010:21)

“Suffering is not only personal, it is interpersonal” (Toombs et al 1995:x). It affects not only the person with the illness, but also those around them: their family, friends and, if in a partnered relationship, their partner. The experience of an illness shared recognises the impact on partners when someone has a life-limiting diagnosis and their remaining life is limited.

Time running out

Time is the universal medium of experience, but it is not a neutral medium. It carries associations and meanings that themselves influence experience.

(Agich 1995:140)

For people whose life is limited, time becomes condensed (Brock 2004). Writing about the impact of her MS diagnosis, Kay Toombs (1995:4) wrote, “the future disappeared”. However, it was not only her future that was affected, that of her husband became “as tentative as mine” (Toombs 1995:4).

The participants in this study have shown that time for the couple is also “running out” when they are living in twilight. Sean recognised that opportunities for resolving the difficulties in his sexual relationship with his dying partner were limited:

There is a sense of urgency on everything. I just want to make sure everything is as good as it can be.

Another participant, Tom, described sex as “short-term medicine”; an escape from his being-in-the-world as an ill man whose life was limited. However, sex also brought with it a sense of isolation and despair:

So like last week, yes, okay, she'd done what she fulfilled to do but then I'm there thinking, well actually I'm on my own again now and I've got to fight this on my own.

The intimate connection that Tom sought with his wife described in previous chapters had dwindled over many years. Tom's life-limiting illness brought the reality of his situation home to him:

... you just go through that little period of time before sleep takes over where everything goes round in your mind and then you think back 20 years, 25 years when things were really brilliant and wishing it to happen again ... It's something I need and it's something that I can't have and it's something I can't do anything about ... I didn't feel that before, I mean before the diagnosis, if we had situations like that, well it was just, you know, things haven't changed, maybe they will next time ... I feel that time is running out, whereas before I felt things were good once and things can be good again, and there's plenty of time to get that right ... and that's not going to happen, because who knows how quickly this is going to take my life away from me.

Tom felt powerless in rectifying his sexual relationship now that his life was "running out". He felt a greater need to connect with his wife since his diagnosis, and the hope for repair that he once held had gone. What might have been was no longer likely, and this knowledge of the end of future possibilities was brought into the present:

Time present and time past
Are both perhaps present in time future,
And time future contained in time past....
... What might have been and what has been
Point to one end, which is always present.

(Eliot 2001a:3)

Participants in this study were not considering "the nearness of the *possibility* of death" (Gullickson 1993:1388. Italics added); their life-limiting diagnosis heralded death as a *definite* event. Contrary to Heidegger's (1962) notion of death as possibility, time for these participants was understood as a matter of absolute finitude. One partner's limited remaining life imposed limits on possibilities for their sexual relationship as a couple.

When will be the last time?

For many participants, knowledge of the finitude of the patient's life brought with it a realisation that their sexual relationship as a couple was also time-limited:

How many more times have we got to be able to make love?

(Nick)

I don't want it to be the last time [we had sex] was the last time ... I just don't want it to be the last time.

(Jane)

As if they were grains of sand in an hour glass, Jane and Nick recognised that opportunities for sex were running out, and these valued means of connecting as a couple were limited. Their taken-for-granted ways of being-in-the-world of their coupled relationship were under sentence.

Heidegger (1962) invited us to consider what it means *to be* in time. For these participants, their being as a couple would irrevocably change when they were no longer able to have sex. Alongside this, there were also moments when the future (or loss of it) created possibilities for being:

I'm not saying I want to jump into bed every day of the week, far from it but ... I value it [sex] two-fold because of ... it's emphasised even more now because when will the last time? When will it happen? When will be the last time?

(Greg)

For Greg, the significance of sex lay in his recognition of an end to their sexual relationship. He valued sex differently because he anticipated a future without it. In recognising the finitude of their sexual relationship, he re-interpreted the present.

The future ~ not simply as a set of events that have not yet been realised, but as the need to come to grips with our own existence ~ generates time and, along with it, generates our interpretations of the world and all that is in it.

(Polt 2010:69-70)

Greg's interpretation of 'time running out' created possibilities for re-interpreting his sexual relationship. For others, however, 'time running out' was construed as an end to possibilities.

A widow-in-waiting

Stella spoke of being in limbo. Her relationship with her husband had changed over the years and she no longer felt that he connected with her. She missed affection in their relationship:

Stella You know what I've got now, I've got a rag, which I take to bed. Oh, it's making me well up (tearful). Well, it's a chiffon scarf (crying). Oh, it's silly (long pause).

BT Take your time (long pause).

Stella I really love that rag ... I do miss, I miss the affection. I don't really, I don't think I miss the sex, but I do miss affection ... He really doesn't care whether I need it or not either. He's closed down completely in that respect (crying).

BT It sounds lonely.

Stella Yeah, because you're, I am a widow, emotionally really, because I've lost him, but I am a slave, so, I can't get on and be a widow because he's still here and he might go on for another 10 years they say ... Not that I want to do anything ... there's no way that I would want to behave like a widow, you know, as if I didn't have a husband ... but I am emotionally, really, except that I'm not because he hasn't died yet.

Stella felt that she was a widow, yet her husband was still alive. She was in limbo, a widow-in-waiting. The loss of affection from her husband signalled an end to their coupled relationship as husband and wife, and the prospect of a lengthy prognosis was daunting for Stella.⁶⁰

Katy also described an end to her coupled relationship:

BT You said earlier that it's not Jake anymore.

Katy Yeah, I lost my husband over a year ago now. It changes their personality. You know, we used to have a good laugh together. I haven't seen him smile let alone laugh for a long time, and I really miss that (pause). And I'm finding it harder to remember how he was, you know. I still try to remember

⁶⁰ Stella's husband died 18 months after this interview.

him coming through that gate [coming home from work] ... it's going to come to an end when he won't even know who I am ... I had a friend whose husband died ... the last thing he said was 'I love you'. And I know I'm not going to get that.

Her husband's brain tumour had changed his personality. He no longer smiled and joked with her, and instead was irritable and demanding. Alongside this, the loss of affection and absence of intimacy meant that, for Katy, the husband she knew had already 'died'.

Stella and Katy only described experiences of disconnecting. They did not experience the re-connecting that Frances described in Chapter 7, and did not anticipate any hope of re-connecting in their husbands' remaining lives. Their stories suggest that their coupled relationship was already dying.

I am aware that none of the male partners described being a widower-in-waiting. I am left uncertain whether this was because they did not make sense of their experiences in this way, or whether this might have been difficult to voice to me as a woman. Might people feel disloyal to speak about this? Is disloyalty towards a woman harder to express to another woman? This may, in part, account for the absence of male narratives on this theme.

Death of the couple

Before he was diagnosed with MND, Paul Brock (2004:37) wrote in a poem to his partner of nine months (now his wife):

So our nine months of Time past
Have bonded Time present with Time future
As our end has become our enduring present

This poem was intended to remind his partner of their "unique past", to give her "a sense of our beautiful present", and "arouse some of those wonderful dreams of the future which we share" (Brock 2004:33). It was written several years before he was diagnosed, and the line "as our end has become our enduring present" carries a particular pathos when contemplating their future as a couple once their life had been invaded by MND.

Participants in this study described the end of their coupled relationship being brought into the present in their being-towards-death-of-the-couple:

If I think about it [the future] too much I get very sad because we don't have a future anymore.

(Julie)

Julie saw the future as an end to possibilities for them as a couple. In her dying, their coupled relationship would also die.

For Kathleen, the end to her sexual relationship with her husband and the loss of physical contact meant she experienced a loss of intimacy and connecting within their coupled relationship:

He'll come and give me a little peck on the cheek and he tells me he loves me and I know he loves me dearly but ... the cuddling and the kissing's gone ... The close relationship you get just to kiss and cuddle and, in the end it's ... We're slowly dying a sort of death really.

The intimacy that had previously defined their coupled relationship was missing. At times of breakdown (life-limiting illness), their coupled relationship was seen in a new light, deficient in the shadow of what it could have been if what had become unavailable were to be present:

When we notice what is unready-to-hand, that which is ready-to-hand enters the mode of *obtrusiveness*. The more urgently we need what is missing, and the more authentically it is encountered in its un-readiness-to-hand, all the more obtrusive does that which is ready-to-hand become ~ so much so, indeed, that it seems to lose its character of readiness-to-hand. It reveals itself as something just present-at-hand and no more, which cannot be budged without the thing that is missing. The helpless way in which we stand before it is a deficient mode of concern, and as such it uncovers the Being-just-present-at-hand-and-no-more of something ready-to-hand.

(Heidegger 1962:103)

No longer connecting as a couple, the being-in-the-world of their coupled relationship revealed itself as "just present-at-hand and no more". This was further exemplified in an example cited by Toombs (2008:6):

You know my wife used to kiss me on the lips, then she kissed me on the forehead, then she patted my shoulder, and this morning when she left, she wiggled my toes.

Little by little, this dying man's wife was withdrawing from him. The disconnecting that he was experiencing as her touch became less and less intimate signified not only the social death that Toombs (2008) referred to; their coupled relationship was also dying.

Although other participants in this study fluctuated between connecting, disconnecting and (for some) re-connecting, a strong sense of loss still pervaded these narratives. Because of this, I have turned to literature on loss to further help me make sense of their experiences.

Mourning the loss

Early bereavement theories embodied concepts of 'letting go', 'moving on' and 'recovering' from loss with an expectation of relinquishing emotional ties (Miller and Omarzu 1998; Neimeyer 2001). More recent theories recognise that grief is not a predictable, universal reaction (Wright and Hogan 2008) and that continuing bonds with the deceased are not, by nature, unhealthy (Klass et al 1996; Neimeyer 2001; Wright and Hogan 2008).

Mourning is no longer considered a restorative process of detachment, but a transformative process involving continuity (Hagman 2001). Instead of relinquishing bonds, theorists recognise that preservation and continuity of a relationship that is meaningful preserves attachment to the deceased (Hagman 2001; Hogan and de Santis 1992; Miller and Omarzu 1998). Indeed, "mourning is not something that can be finished" (Gaines 1997:568).

Mourning involves the transformation of the meanings and affects associated with one's relationship to the lost person ... while at the same time ensuring a continuing experience of relationship with the deceased.

(Hagman 2001:24)

I would suggest that mourning the loss of a sexual relationship involves transformation of its meaning while ensuring a continuing experience of relationship that is formed on new meaning. For many participants, this transformation of meaning enabled participants to maintain their coupled relatedness rather than merely "living alongside one another" (Jacky).

Attig (1996) suggested that grieving involves re-learning our world. As beings-in-the-world, this also involves re-learning our world of relationships. This re-learning involves a “transition from loving in presence to loving in absence” (Attig 2001:34). When experiencing loss, we re-evaluate and modify our understandings in the context of our worlds. Thus loss becomes woven into the “richly complex fabric of our lives” (Attig 2001:34).

In grieving, we re-learn roles and relationships (Attig 2001). After someone we love has died, re-learning the world of relationships involves re-learning “how to be and act in the world” (Attig 2001:41). Similarly, when our habitual ways of connecting with our partner are no longer possible, re-learning the world of our coupled relationship involves re-learning how to relate to each other in the world of that relationship.

The grief that is experienced as a relationship changes may mirror the way that grief is experienced after bereavement: a desire for what was (the past), and the need to adapt to what is (the present), while moving towards the uncertainty of what will be (the future). The Dual Process Model of Grief was developed by Stroebe and Schut (1999) in recognition that grieving is a dynamic process. This model explains the experience of grief in terms of oscillating between confronting and avoiding the loss (Stroebe and Schut 2001). This oscillation is a coping strategy and recognises that adjusting to loss involves both ‘loss-oriented’ and ‘restoration-oriented’ processes (Stroebe and Schut 2010).

‘Loss-orientation’ involves experiencing the sadness and grief of loss, a searching for what once was, and an appraisal of the meaning that that which was lost once held (Stroebe and Schut 2010). ‘Restoration-orientation’ involves the struggle to re-orient oneself in a changed world; re-thinking and re-arranging one’s life in the face of this loss (Stroebe and Schut 2010). Research with bereaved people has shown that this process of confrontation and avoidance is necessary for adaptive coping, and the emphasis that different individuals place on each behaviour helps to explain how different people grieve (Carr 2010).

This study has shown that the threefold experience of connecting, disconnecting, and re-connecting are experienced within the constitutive pattern of being-towards-death-of-the-couple. It is feasible that people living with life-limiting illness who are more able to engage with the process of ‘restoration-orientation’ attribute new meaning to their coupled relationship and recognise alternative ways of maintaining connecting with each other. For

some, this may also bring about re-connecting. Alternatively, when sexuality and intimacy are experienced as 'silent bedfellows', disconnecting may persist if individuals within the coupled relationship are unable to move from 'loss-orientation' when the usual ways of being-in-the-world-of-their-coupled-relationship are lost.

This study raises questions about what makes it possible for some couples to maintain connecting, where others do not achieve this. How does this impact upon partners' experiences in bereavement? How is grieving affected by the 'connectedness' of a couple's relationship before bereavement?

Conclusion

The experience of being human is both dynamic and complex. A life-limiting diagnosis disrupts the life course for the person who is dying, and brings with it an irreversible end to human bonds. This study has also shown that it heralds the death of the coupled relationship. One person's being-towards-death when living with a life-limiting illness achieves a hold on the present and not only limits possibilities for connecting as a couple, but also rehearses the death of their coupled relationship.

The future ain't what it used to be no more.

(Steinman 2006; 1989)

Chapter 9: What place do sexuality and intimacy have in healthcare practice?

Introduction

The focus on quality of life in caring for people who are dying is centred upon meeting the physical, psychological, spiritual and social needs of patients and their families (Addington-Hall 2007). Previous chapters have shown that the experience of a life-limiting illness is an assault on the whole person; it impacts not only the physical body, but also has emotional and social ramifications for coupled relationships. These are experienced as connecting, disconnecting and, in some cases, re-connecting, in a couple's remaining life together.

If sexuality and intimacy are legitimate aspects of holistic healthcare, then it is important to ask how participants experienced sexuality and intimacy in their interactions with healthcare professionals. To what extent are sexuality and intimacy recognised within the provision of holistic healthcare? This chapter discusses participants' experiences of healthcare professionals addressing sexuality and intimacy, and presents some of their suggestions for healthcare practice.

Experiences of discussing sexuality and intimacy with healthcare professionals

For the majority of participants in this study, questions regarding sexuality and intimacy had not been raised by any of the healthcare professionals involved in their care. Very few referred to reading written information, and some described being told about the effect of their disease on sexual function:

The doctor said it [MND] would make no difference to you sexually at all.

(Greg)

The consultant just said a couple of times 'oh, it won't affect that part of you'.

(Sally)

These participants reported feeling reassured to hear that MND would not affect them sexually. However, this information neglected to consider the impact of their illness on the coupled relationship. Although MND does not physiologically affect sexual function (Talbot and Marsden 2008; Talbot et al 2010), this study has clearly shown that some people living with MND experienced disconnecting in their coupled relationship.

It could be considered reassuring that none of the participants in the cancer group reported being told that their sexuality would not be affected. However, most merely experienced silence on this matter.

A silence surrounding sexuality and intimacy

Apart from four of the participants recruited via the psychological support services from one hospice, no one described having shared their thoughts, feelings and concerns about sexuality and intimacy with any healthcare professionals. One couple recalled being given an opportunity to discuss these issues, but did not feel a need to do so at the time. For most participants, the first time the subject was raised was when they were invited to take part in this study.

It isn't spoken of ever, and hasn't been spoken of to me when I've been in the hospice or with the doctors at all. Perhaps it doesn't rate with them.

(Jim)

The silence that these participants experienced from healthcare professionals, and their perception that "it doesn't rate with them", echoes the findings of other research (de Vocht 2011; Hawkins et al 2009; Hordern and Street 2007a; Hordern and Street 2007b; Lemieux et al 2004), further highlighting that this is a neglected area of healthcare practice.

Les had been diagnosed with prostate cancer three years before I interviewed him, and, as a result, had erectile dysfunction:

BT When you were first diagnosed with prostate cancer, or any time since, did any of the doctors or nurses discuss sexuality with you?

Les No. No-one said to me how's it affecting your sex life or can you still get a stirring or. No, you are the first one.

Les was 70 years old. Since his diagnosis, he had received treatment from surgical and oncology professionals, and had been under the care of a hospice for the preceding six

months. His age did not preclude him from having concerns about the impact of his disease and treatment on his relationship with his wife, yet he was never given an opportunity to discuss this. None of the staff in any of these settings had broached the subject with him.

Several authors suggest that sexuality is neglected in older people because of ageist assumptions that healthcare professionals hold (Crouch 1998; Gott 2005; Nursing and Midwifery Council 2009). Indeed, studies in Australia (Hordern and Street 2007a; Hordern and Street 2007b), America (Matzo and Hijjazi 2009), the United Kingdom (Gott et al 2004; Haboubi and Lincoln 2003; Taylor 2007) and Sweden (Saunamäki et al 2010) have endorsed this view. However, this study has shown that age is not the sole barrier to healthcare professionals broaching these conversations. Even though Michelle and her husband were newly married and in their early thirties, sexuality had not been addressed by any of the healthcare professionals involved in their care:

I wish I'd been able to talk about this with somebody before I had to deal with it with Dave ... I did struggle to find the words to say to him ... It's such a shame that it wasn't addressed ... I didn't have the option to talk to somebody about it before it got to the point with me where it was such a problem that we were going to have to go to the GP and say 'can you give him something to stop his urges?'

(Michelle⁶¹)

As explained in Chapter 6, Michelle had been unable to explain her thoughts and feelings to her husband, and their mismatched sexual needs were a cause of many arguments. Because none of the professionals had ever broached the subject with her, she was unsure whether it was appropriate to raise it with them, and felt "embarrassed" to do so. The disconnecting that Michelle experienced might have been compounded by the silence of these professionals:

No-one had ever talked to me about it, how to deal with it and maybe it is something that people need to be helped to deal with, you know, in situations like this. I'm sure there's many people that have to go through it ... I think when you're feeling sad about something it's hard to, hard to describe it and put it into words to the person that you love isn't it, and explain to them why.

⁶¹ Michelle was bereaved at the time of the interview.

If Michelle had been able to voice her concerns and discuss the cause of these arguments with a healthcare professional, they might have been able to facilitate a discussion between her and her husband. It is feasible that such a conversation might have enabled Michelle and Dave to re-interpret each other's differing sexual needs since he had become immobile. Any emerging understanding might have reduced the disconnecting they experienced, and made re-connecting possible.

One conversation that did take place with a healthcare professional arose when Nick's wife was told she would need a PEG tube permanently inserted into her abdomen. Nick recounted asking a nurse whether his wife's proposed PEG tube would impede sexual activity, and recalled being told it would not prevent them from having sexual intercourse. However, their experiences were not as straightforward:

Since she had the PEG put in, it started to change things ... to me it seems a sort of delicate thing and obviously you don't want to physically upset the tube and I'm very aware of that ... and it means you've got to take more care and obviously it's something that's aesthetically it's not sexually appealing, is it, so there's that angle as well ... initially she put a bandage round her waist to sort of protect the tube, which was okay but it's a bit off-putting.

Nick and his wife had tried bandages to hold the line in place, but as visual imagery was important in their love-making, changed to using tight clothing to hold and conceal the PEG. Because of their concerns about the line being pulled, they modified their sexual positions to avoid abdominal contact. It is clear from Nick's narrative that considerable adjustment was needed to enable them to maintain their sexual relationship in a satisfactory way:

We've been given no guidance at all, so all this is worked out for ourselves.

Although Nick and his wife were able to experiment until they found solutions that suited them, other couples might not be able to achieve this. This suggests that there could be a need for written information, or a role for healthcare professionals in opening up these conversations.

You're on your own

Some participants facing treatment for cancer who had voiced their concerns to healthcare professionals felt unsupported. When Angela was told she would need a mastectomy, she was concerned about its impact on her sexual relationship:

I can remember saying to them, how will my husband feel? ... How is he ever going to find me attractive again? And all they said is, 'that's something you've got to work out between the two of you'.

Bert also described feeling alone in managing the impact of his disease on his relationship. Bert had become impotent as a result of surgery for prostate cancer. Having unsuccessfully tried pellets, and not wanting to inject himself, celibacy had seemed the only option:

There was no emotional counselling at all ... it was something we had to work out ourselves.

Both Angela and Bert described experiences of disconnecting in Chapter 6. Even though the changes in their relationship arose because of the effects of treatment, they had not been offered any support in maintaining intimacy or connecting. They were 'on their own'.

This is one of my big gripes about the relationship changes, and when somebody is diagnosed, the relationship just totally changes in every aspect and there doesn't seem to be much support for that. There is support for the carers [from a local hospice], there is support for the patients, but there is not much support for the actual relationship between the two ... Some couples come closer together, some it drives them apart, and there doesn't seem to be any sort of help in that area.

(Sean)

The silence surrounding sexuality and intimacy was compounded by clear messages from professionals and organisations that couples would not be supported with these issues. Left to 'sink or swim', participants experienced both connecting and disconnecting in their coupled relationship as they grappled with their life-limiting illness and the effects of disability, illness and treatment. For participants in this study, there was a clear gap in the provision of holistic healthcare.

A disenfranchised loss

The silence surrounding sexuality and intimacy and participants' experiences of being 'on your own' suggest that the loss experienced by patients and their partners when they experienced disconnecting was disenfranchised. Kenneth Doka (1989) first identified the concept of 'disenfranchised grief' when considering the experiences of homosexual men whose partner had died. Unlike the support that was given to heterosexuals, Doka (1989) realised that the grief experienced by homosexual men when their partner died was not acknowledged or recognised by others.

'Disenfranchised grief' is defined as the "loss of a meaningful and significant attachment" that is unrecognised and not validated by others (Doka 2002a:xiii). When people experience disenfranchised grief, their loss "cannot be openly acknowledged, socially validated or publically mourned" (Doka 2002a:xiii). Disenfranchised grief extends far beyond the experiences of homosexual men, and is now understood to include the grief experienced following a wide range of losses including miscarriage, when an ex-partner dies, when a home is destroyed, when a pet dies, and more (Doka 2002b).

Even though, for most participants in this study, the person with whom they had a "meaningful and significant attachment" (Doka 2002a:xiii) was still alive, individuals' way of being-in-the-world of their coupled relationship underwent change when one partner had a life-limiting illness. While some participants were able to adapt and change, finding new meaning in alternative ways of connecting, others experienced disconnecting and expressed deep sadness. When one partner did not acknowledge or validate the loss of their sexual relationship, individuals experienced disenfranchised grief; the significance and meaning of the loss they experienced was minimised, rejected or unrecognised by their partner. This was experienced as disconnecting in their coupled relationship.

When I have presented some of the new understandings arising from this study to a variety of audiences, I have frequently been thanked by people affected by life-limiting conditions "for naming the elephant in the room". More and more, I realise that people's experiences of sexuality and intimacy are unrecognised, and that their hidden sorrow of disconnecting remains unspoken. Because sexuality and intimacy remain taboo topics in healthcare (Hordern et al 2009; Saunamäki et al 2010), there is no acceptable forum for people to voice their sadness, disappointment or feelings of rejection. When people's experiences of disconnecting, and the associated sadness they experience goes

unrecognised, their loss is disenfranchised. Their sorrow remains hidden and is not validated by others.

Before considering a role for healthcare professionals in addressing these aspects of people's lives, it is useful to consider how participants in this study felt about talking about these personal and sensitive issues to me, as a researcher.

Experiences of talking about sexuality and intimacy in the research interviews

At the start of the second interview, I asked each participant how they were after the first interview in order to establish how I should best manage the second interview. My concerns centred on whether they had been excessively tired, or were distressed by some of the content, but chose to ask this as an open question: "Before we start, I wonder, can you tell me how you were after the first interview?" Several participants volunteered information about the interview's beneficial effects.

Although research interviews, with their purpose being to collect data, do not intend to have a therapeutic effect, it is clear from some of the participants interviewed that direct benefit was experienced from taking part in the study:

There's a tendency to shove certain matters to the back of one's mind and ignore them. It's like doing an appraisal with somebody, that you bring thoughts, you focus on things that had just been rumbling around in the back and it just brings things forward and makes you think about them a little.

(Nancy)

The process of describing an experience is, in itself, an interpretative process (van Manen 1990). Nancy valued the opportunity to reflect upon her experiences. For others, this reflection brought about new meaning:

Maybe it's done me good to talk about it, get it actually out of my head how I ... rather than feeling guilty about it all, but there was reasons why I was the way I was. I think it was completely normal to feel like that.

(Michelle)

In the re-telling of these experiences, Michelle was beginning to reach new understanding by normalising them. It was beyond the purpose of this study to explore the effect of these experiences on bereavement, but I wonder whether Michelle would have needed further opportunities to reflect on her experiences in order to make sense of them and assuage the guilt she had been feeling.

Other participants spoke of the interviews “bringing things to the surface” and triggering conversations between them as a couple. In the second interview, Nancy referred to a conversation she and her husband had had after the first interview:

We talked a little bit, how it affected our relationship and intimacy and that sort of slight drifting apart ... Whether it's made us any closer or not, I've no idea, because we didn't, we didn't dwell on it for too long. But it probably does influence one's thoughts about each other, really, and maybe it just brings things into a little bit more perspective just because we've raised the issue that we generally don't discuss.

Stuart also described the benefit of hearing his wife's perspective:

It was probably quite useful that we talked about it. It clarified how [my wife] was feeling for me and vice versa, which was a good exercise for us, so we had gains from the experience, I think ... It was quite useful to hear [her] actually say that she did feel her libido was down and things like that. I mean it's nice to have these things just said out rather than just, you know. I told her I'd said about intercourse being painful for her, and she didn't sort of say, well it's not that bad or anything, so it obviously is. You know, so it confirmed sort of my interpretation of events for me, and added her sort of feelings a little bit, so I think that was quite useful for both of us.

Stuart spoke of the reduction in their sexual relationship in physical terms. In addition to learning about his wife's reduced libido, Stuart found it helpful to have his belief confirmed that she found intercourse painful, even though this confirmation was nothing more than absence of any denial. He didn't expand upon why this was helpful (and I omitted to ask this), but the conversation between them was clearly beneficial and perhaps minimised any potential feelings of rejection. What is clear, however, is that their conversation, prompted by the research interview, altered their perspective in some way. I had not suggested that they speak to each other; I merely asked each of them about their

experiences and listened empathetically. I wonder whether such a conversation could not have been prompted by any of the healthcare professionals involved in his wife's care.

The benefit of talking to an attentive listener was further exemplified by Frances:

I actually talked to Alistair about, we had a conversation about the fact that, about our sex life and he actually admitted for the first time ever, 'yes it never really worked did it'. And that for me is a fantastic thing that he's prepared to actually say that, admit that. That is a very positive result of the interview as it made me talk to him, and that was probably a conversation I would never have had with him if you hadn't come and asked me about it.

Some of the re-connecting that Frances described in Chapter 7 arose in response to the first interview, illustrating a profound effect of research interviews on people's experiences. It is evident from her description that research interviews can be both "cathartic" and "healing" (Lowe and Gill 2006:591), as they provide opportunities to discuss unresolved issues (Dickson-Swift et al 2008).

It is important, however, to recognise that the ease with which people spoke with me might not reflect a similar ease in talking to healthcare professionals involved in their care. My status as an "acceptable stranger" (Clarke 2003:731) might have facilitated disclosure because our relationship was time-limited (Cotterill 1992). Indeed, one participant (Richard) said that he would only want to speak to an "independent" person as he would not want disclosure of his sexual preferences to influence his relationship with his doctor or nurse.

The intent of research interviews is not to effect change, but to understand the world of others (Romanoff 2001). Nonetheless, in my role as listener, companion and witness as participants shared their experiences, I wondered whether this was not a similar function of professionals who care for people living with life-limiting illnesses.

A role for healthcare professionals?

The purpose of this Heideggerian hermeneutic study was to understand how people make sense of their lived experiences. In their story-telling, many participants considered the role of healthcare professionals in discussing sexuality and intimacy.

If I had questions, I'd ask

One of the participants saw no difficulty in discussing sexual issues with her doctor. Grace (in her eighties) was not at all reticent about discussing sexual issues and was not reliant upon healthcare professionals broaching the subject with her:

Grace I talk quite happily about sex, it doesn't bother me and so I don't really need to talk to a doctor about it, if you see what I mean.

BT And if you had something you wanted to ask a doctor?

Grace I'd ask.

Interestingly, the men who described using Viagra (Jim and Clive) sought this drug from their GP, but did not recall any conversations about its impact upon their relationship. They had presented with erectile dysfunction as a physiological problem, and it appeared to have been treated in purely physiological terms. Any potential for disconnecting discussed in Chapter 6 had not been recognised, and I am curious as to why participants did not raise these relationship issues themselves.

What's the point in talking to healthcare professionals?

Most participants were unable to identify a role for healthcare professionals in addressing this aspect of their life. Although this might be because they had no prior experience upon which to base this, it is important to recognise that some participants did not perceive a need for external help:

Cheryl We don't need help, advice, we've got a very solid relationship. Now, it may well change if I was paralysed, it may well happen. Even then, I think we would feel we would want to sort things out ourselves.

BT Wanting to sort it out yourselves because it's something that's private?

Cheryl Not particularly private, there's nothing they can do. We've already sorted it. We can talk about it. That is the main thing, we can talk about, have a laugh about it, and we have a very serious, loving, serious, you know, if we want to be. So, an outside person, I see no necessity, and I'm sure [my husband] would agree.

Couples who felt able to work things out for themselves did not see the value of talking to healthcare professionals. This supports the findings of other research (Hordern and Street 2007a). However, other participants who could see no benefit in these conversations were more fatalistic, saying “what’s the point, what can they do?” This suggests either a perspective that ‘nothing can be done’; or that their experience of healthcare professionals is as ‘do-ers’ rather than someone with whom they could explore their thoughts, feelings and concerns about sexuality and their intimate relationship.

Views like these conflict with the notion of healthcare practice being holistic, addressing not only the physical, but also the emotional and social aspects that matter to each individual. Even though some participants did not see a need to speak about this aspect of their lives, they recognised that others might benefit from conversations with healthcare professionals.

An optional conversation

On the whole, participants felt that healthcare professionals should provide people with an opportunity to talk about issues concerning sexuality and intimacy. However, they consistently stated that any such conversations should be optional:

It has to be an offer doesn't it, it has to be an offer of a service but you've got to decide whether you want to actually accept that service.

(Angela)

It would be intrusive of people to just come barging straight in and saying ‘what’s your sex life like?’ I’d say ‘mind your own business’ ... By all means broach it and let people know what is available by way of counselling and all the rest of it, but not to push it too hard ... Tell them what’s available and let them make their own choice.

(Barry)

If it was **offered**, then you’d have a choice to take it or not.

(Maureen)

I am mindful that the participants in this study might have had a degree of comfort in speaking about sexuality and intimacy that was not shared by those who did not take part. Given that some people chose not to take part because the subject was “too private”, this

next suggestion (on a reply slip from someone who chose not to participate in the study) endorses the view that conversations with healthcare professionals should be optional:

Healthcare professionals could offer a checklist of potential items for discussion, which could include 'personal relationships' (not 'sexuality'). The patient then has the choice of whether they wish this subject to be raised.

(61-70 year old female patient. Emphasis in original)

This suggestion raises an interesting point about language. As discussed in Chapter 4, 'sexuality' tended to be construed as an embodied, sexual experience. In contrast, the term 'personal relationships' does not presume sexual activity, and could implicitly recognise the place of connecting, disconnecting and re-connecting in people's lives.

Who should broach these conversations?

I did not ask participants who would be the most appropriate person to broach these conversations, though some people offered their considerations:

I think it would have to be somebody that you felt empathy with to discuss it, I mean I wouldn't sort of want an OT 'cause I mean they can change so often, popping in and saying well now I think I'll fit the loo rail and then how's your sex life? ... I could certainly discuss it with my nice doctor [GP], but then you see I don't need to see her, and I don't know that, to ring her up and say can we come in and, it just wouldn't occur to me that she'd be able to contribute very much to it.

(Rita)

Rita's evaluation of the role of her GP and the OT (occupational therapist) are very telling. De Vocht (2011), in her Dutch study, had imagined being able to ascertain which professional would be best suited to discussing these issues. However, she was surprised to learn from patients and partners that the professional discipline was not important. What Rita has explained here is that, in order to feel comfortable discussing sexuality and intimacy, the professional needs to be approachable, should indicate the appropriateness of such conversations, and should broach the subject in an appropriate manner.

Participants in this study were divided in their views as to whether this conversation would be preferable with a healthcare professional of the same or opposite gender:

I don't think I could talk to a man about it.

(Julie)

I find it very easy to talk to men, always have done. I'm not embarrassed at all at talking to them. Sometimes talking to men, they know different things to women, don't they, so they can talk the man's side of things.

(Katy)

I think it's easier to talk to a woman, to be honest ... Because if you're telling a man and you're trying to measure up, men always try and measure themselves against each other. In a subconscious way, even when they think they're not, they are ... If you're telling a man that you've had problems with erection and, it's a bit, although they're not, you could think they was sort of, 'oh well, well I haven't' (Pause). I think I share more with; I share more with you than I could with any bloke.

(Sean)

It is apparent from these examples that the preferred gender of the healthcare professional is a matter of individual choice, and that this can influence the ease and value of such conversations. Notably, whether the conversation occurs alone or with their partner present can influence people's preference for gender:

It's easier coming from a woman ... especially when [my wife] is there as well.

(Nick)

However, because Nick and Sean did not have any experience of discussing sexuality and intimacy with a male healthcare professional, I wonder if their hypothetical views might change with new experiences. Reporting on research conducted in the Netherlands, where patients with cancer and their partners were asked their preferences regarding communicating with health professionals about sexuality and physical intimacy, de Vocht et al (2011) found that the gender and age of the healthcare professional ceased to be important, despite people's initial expectations:

Doesn't matter if it's a man or a woman; it's the type of person that counts. [Mike]

(de Vocht et al 2011:614. Emphasis in original)

A younger person would have been fine ... It could have been an older person as long as I got the feeling that it's **me** that mattered. [Edith]

(de Vocht et al 2011:614. Emphasis in original)

These quotes suggest that what is of greater importance is the professional's approach. This includes acknowledging people "as a person" (de Vocht et al 2011:613), generating "a sense of trust" (de Vocht et al 2011:614) and giving people the opportunity to tell their story.

How should these conversations be broached?

Participants in this study volunteered some useful points about professionals broaching conversations about sexuality and intimacy. Julie identified a member of the healthcare team she imagined she could speak to if she and her husband had been unable to make the adjustments, sexually, that they had. However, she would not want this to be a shared conversation:

I don't want [my husband] to know all my hang-ups ... He thinks I worry about stupid things.

Tom also recognised the value of one-to-one conversations:

It's a subject that I don't think my wife would ever want to talk to anyone about. Even when I was healthy, it was difficult enough, but then I may be wrong ... maybe it's something that may be worth broaching with her, but certainly not in my company. I think it may be helpful for someone to talk to Deidre about it out of my earshot, but how successful they'll be or where they'll get, I just don't know.

Nancy did not consider that she would ever wish to discuss these matters with a healthcare professional. However, she recommended that this be offered as a one-to-one conversation:

I don't go to the hospital with [my husband] ... I didn't want to become an Indian wife ... When you get Indian couples coming in, and it's the woman who's got the problem, the man answers all the questions, and he speaks for her and everything goes through him. And I felt a bit like that [when my husband attended the hospital with me]. Not, you know, probably because [he] was asking questions pertinent to him, but I wasn't sure I wanted him to ask those questions. I wanted some control

over my disease. If I didn't want to talk about something, I didn't want to talk about it. But when you're sharing it with somebody you've got to allow them their space too. I wanted to have that freedom of discussion between, you know, the professional and me ... if I wanted to talk about things that I didn't want to talk about in front of [him], I could. If I had worries that I didn't want him to worry about particularly, then I could still express them.

(Nancy)

Shared consultations are beneficial because each person is aware of the same information, but the patient and their partner might each benefit from opportunities to discuss their concerns in a one-to-one consultation (Cooper and Guillebaud 1999). In coupled relationships, each person is likely to be processing information differently, and constructing their own meaning from the experiences. To offer a 'one-size-fits-all' approach to practice does not recognise these individual needs. Even though some people would prefer one-to-one conversations without their partner present, others recognised the value of three-way conversations:

It's often difficult to talk about things between yourselves and sometimes having an objective third party who is not emotionally involved might be helpful.

(Nancy)

It's a shame we couldn't work it out on our own ... we just need a mediator.

(Sean)

Unless healthcare professionals recognise the potential for connecting, disconnecting and re-connecting within the coupled relationship when one of the partners has a life-limiting illness, any such need for a mediator is likely to be unmet. Some participants suggested that the 'door' to conversations about sexuality and intimacy could be 'opened' at any time:

I don't think it would hurt to say anything almost straight away [on diagnosis]. To say, you know, there is help, we can discuss it, there are people that have gone through the same thing.

(Michelle)

Several authors have suggested that, on diagnosis, sexuality and intimacy might not be issues that are of greatest concern (de Vocht 2011; Little et al 2001; Yaniv 1995). Indeed,

there is some research evidence which supports this view (Southard and Keller 2009). However, the focus of oncology professionals on curative treatment has resulted in patients assuming that sexuality is not important, which results in them feeling reluctant to raise their concerns (Hordern and Street 2007b).

For those with life-limiting conditions such as MND that do not have any prospect of cure, the absence of the 'distraction' of treatment might possibly render relationship concerns higher priority at that time. Some people might wish to discuss these matters on diagnosis and others might not. However, indicating that this is a topic that could be discussed if people want to, now or in the future, leaves the 'door' open for such conversations.

Michelle's suggestion (above) also indicated the value of hearing from a healthcare professional about the experiences of others who have 'gone through it'. This opportunity for learning from shared experience was echoed by Susie:

They'll [healthcare professionals] say 'I have had patients before and their coping strategy was to do that', or they might have several examples of how other patients found ways to deal with that. And of course we're all interested in hearing other people's coping strategies.

The benefit of hearing about the experiences of others is endorsed by findings from Stead et al (2003:669), indicating not only the value of learning from others, but also the value of shared experience in determining normality:

It would make you think that because other[s] ... have gone through it, what you're going through is nothing different; otherwise you feel that you are different. It gives you confidence if you know others are experiencing the same problems.

These findings indicate that there is a place for discussing sexuality and intimacy in healthcare, so leaves me wondering why healthcare professionals do not address this aspect of people's lives.

Why don't healthcare professionals raise issues of sexuality and intimacy?

Because there has been so little research undertaken to identify the issues related to sexuality for people with life-limiting illness, the paucity of research to understand the

perspectives of healthcare professionals caring for people who are dying is unsurprising. Kutner et al (2001) undertook a cross-sectional study to understand the prevalence and severity of symptoms in hospice patients from the perspective of the healthcare professionals providing their care. Using the Memorial Symptom Assessment Scale⁶² (MSAS), staff at the weekly inter-disciplinary meetings in 16 American hospices were asked to state whether or not the patients reviewed experienced the symptom, and to rank each patient's symptoms in order of troublesomeness. Data were collected pertaining to 348 patients. The hospice staff only identified 3% of patients as having 'problems with sexual interest or activity' and 13% as having problems due to 'change in self- image'.

Without comparable data of the symptoms actually experienced by these patients (as recorded by the patients themselves), it is not possible to conclude whether or not the views of these staff were a conservative estimate of symptom burden in relation to sexuality. However, as staff had indicated that they were unable to rate 'problems with sexual interest or activity' or 'change in self-image' for 63% and 30% of patients respectively, this does suggest either a reluctance of staff to ask about these issues, or a view that they are unimportant or irrelevant to hospice care.

This has been further endorsed in research by Matzo and Hijjazi (2009). Using a mixture of face-to-face and telephone interviews with 20 nurses from two different American hospices, they found that 60% (n=12) of these nurses reported that they had never raised the subject with patients. A further 15% (n=3) rarely did. These nurses described embarrassment and a lack of training in this area, though also indicated assumptions that restricted their practice. As one nurse said:

Most of my patients are so sick and old that I just honestly don't think there would be these issues with someone facing their death.

(Matzo and Hijjazi 2009:275)

The nurses in their study did not consider sexuality to be a priority and believed that patients would raise the subject if they had concerns.

⁶² The MSAS was validated for use by cancer patients to record the prevalence of a wide range of physical and psychological symptoms, ranging from pain and nausea to irritability, sadness and difficulty concentrating (Portenoy et al 1994). In this study, the MSAS was completed by hospice providers rather than patients so that healthcare staff's awareness of patient symptoms could be determined.

Because there has been so little research that specifically considers the views and experiences of healthcare professionals in addressing sexuality with people who have life-limiting illnesses, studies in other areas shed further light. Guthrie (1999) undertook a grounded theory study in Scotland to understand how nurses' views of sexuality might influence the care they gave. Interviewing 10 staff nurses from a surgical unit, she found a reticence to talk about sexuality with patients. Staff cited lack of time and lack of privacy as reasons for not discussing sexuality with patients, and a belief that, if it was important to patients, they would ask. Guthrie (1999) acknowledged that, while lack of time and lack of privacy might be valid reasons, they might also be avoidance strategies which reflect the reticence and embarrassment these nurses described.

In Sweden, Saunamäki et al (2010) surveyed 88 registered nurses working in medical and surgical wards. They found that 92% of these nurses stated that they understood how the patients' illness and treatment might affect their sexuality, and 63% considered sexuality to be a nursing responsibility. Despite this, most nurses (81%) stated that they did not make time to discuss patients' concerns regarding sexuality. 86% considered sexuality too private a topic to discuss with patients, and over 40% believed that sexuality should not be discussed unless patients broached the subject first. These findings concur with those of Magnan et al (2005), who asked similar questions in their survey of medical and surgical registered nurses in one American hospital. They found that 72% of the nurses (n=148) felt sexuality was a nursing responsibility, yet only one third reported making time to discuss this with patients.

Unsurprisingly, nurses who reported greater discomfort and less confidence in their ability to address patients' concerns about sexuality also felt that it was too private an issue to discuss with patients (Saunamäki et al 2010). Nurses with greater confidence in their ability to meet patients' needs regarding sexuality were more likely to make time to discuss it (Magnan et al 2005).

In a larger UK study that examined the views of a range of 813 healthcare professionals (doctors, nurses, physiotherapists and occupational therapists), Haboubi and Lincoln (2003) found similar results. 90% of the professionals they surveyed recognised sexuality as an important part of holistic care, yet 68% said they had never initiated conversations about sexuality with patients. Respondents described lack of time (67%), embarrassment (50%) and lack of training (79%) as barriers to these conversations. Their findings, from acute and rehabilitation settings, are echoed in Stead et al's (2003) study of oncology

doctors and nurses in England. Lack of knowledge, embarrassment and lack of experience were, once more, the reasons given for not discussing sexuality with patients.

Attempting to understand the views of healthcare professionals in more depth, Hordern and Street (2007a; 2007b) interviewed 32 healthcare professionals (doctors, nurses, social workers, physiotherapists and an occupational therapist) working in the field of cancer. Through thematic analysis, they found that these Australian professionals' perspectives on discussing sexuality and intimacy fell into one of five 'clusters', as shown in Table 4.

Despite giving holistic definitions of sexuality and intimacy, Hordern and Street (2007a) found that professionals were much less comfortable with discussing non-physical aspects of care. Most prioritised information on treatment or cure, perceiving this to be of greater importance, and used defensive strategies to avoid conversations in which patients could express their concerns about sexuality and intimacy, and the effects of treatment on their relationship. It is clear from their study that information alone will not address these perspectives or change the care given by healthcare professionals.

Table 4: Healthcare professionals’ perspectives on discussing sexuality and intimacy: findings summarised from Hordern and Street (2007a)

Cluster	Key features of professionals’ behaviour
“It is not life or death”	<ul style="list-style-type: none"> • Assumed patient priorities were limited to prognosis, treatment and survival. • Conversations with patients were “formulaic” (p.1712) and focussed on information-giving.
“I manage to avoid the topic”	<ul style="list-style-type: none"> • Professionals described their own “lack of comfort” (p.1712) • They assumed someone else in the team would address sexuality. • If it was raised, information-giving focussed on medical issues such as contraception, fertility and menopause. • Lack of time and privacy were given as barriers to discussing sexuality and intimacy.
“I can’t expose my vulnerability”	<ul style="list-style-type: none"> • These professionals were concerned that colleagues would criticise them if they discussed sexuality and intimacy, and described using humour with patients to “make light of a bad situation” (p.1713).
“It is a risky business”	<ul style="list-style-type: none"> • Professionals avoided conversations where they might be misinterpreted or might look naïve. • They avoided conversations with patients from other cultures, as well as those that were of a similar age to their own parents. • They avoided conversations with single patients: “not wanting to rub their face in it” (p.1713).
“Negotiated communication”	<ul style="list-style-type: none"> • These reflexive professionals recognised that their own comfort with the topic influenced their behaviour with patients, and sought to establish “patient-centred communication”.

Kotronoulas et al (2009) conducted a literature review of studies published between 1980 and 2008 to consider the views of nurses working in oncology settings. They found that lack of knowledge was often cited as a reason for not addressing sexuality in nursing practice. However, consistent with the more recent findings of Saunamäki et al (2010), nurses who reported higher levels of knowledge still avoided the topic.

Research has consistently shown that healthcare professionals do not broach sexuality even when they recognise its importance (Haboubi and Lincoln 2003; Magnan et al 2005; Saunamäki et al 2010). It is feasible, however, that these studies have generated socially acceptable responses, so the proportion of respondents that indicated that sexuality is an important aspect of care could be an over-estimate. Having said this, it is notable that there is a mis-match between healthcare professionals' rhetoric and their clinical practice.

From these studies in a variety of countries, healthcare professionals said they lacked training (Haboubi and Lincoln 2003; Matzo and Hijjazi 2009; Stead et al 2003) and felt ill-prepared (Lavin and Hyde 2006) to address sexuality. It is evident that knowledge is not the sole factor in determining whether healthcare professionals address sexuality with patients. They hold beliefs that sexuality is not a priority for patients (Hordern and Street 2007a; Hordern and Street 2007b; Magnan et al 2005; Matzo and Hijjazi 2009; Saunamäki et al 2010), and is too private a topic to discuss (Magnan et al 2005; Saunamäki et al 2010). Issues of confidence and personal comfort (Lavin and Hyde 2006; Magnan et al 2005; Matzo and Hijjazi 2009; Stead et al 2003) impede healthcare professionals in identifying patients' needs regarding sexuality. This results in them waiting for patients to raise the topic first (Guthrie 1999; Kotronoulas et al 2009; Lavin and Hyde 2006; Matzo and Hijjazi 2009; Saunamäki et al 2010; Stead et al 2003).

In order to identify how healthcare professionals might better address sexuality and intimacy, it is useful to consider some of the models or frameworks available.

Models for addressing sexuality in healthcare practice

There are a plethora of models to support healthcare professionals in discussing sexuality with patients. The first of these was developed by Annon (1976), an American psycho-sexual therapist. His PLISSIT model recognises differing levels of practitioner expertise (Annon 1976), and enables healthcare professionals to identify their own strengths and limitations (Davis and Taylor 2006). The acronym signifies four levels of involvement:

Permission, Limited Information, Specific Suggestions and Intensive Therapy. In Annon's (1976) experience, most sexual problems can be resolved if people are given permission to be sexual, are given limited information to validate their behaviour and dispel myths and misconceptions⁶³, and, if needed, are given specific suggestions for resolving sexual difficulties. According to Annon (1976:47), most people's problems would resolve with this "brief therapy", and would not require referral to psychosexual therapists for intensive therapy:

Many sexual dysfunctions of longstanding concern to people need only understanding and a commonsense approach for their resolution.

(Annon 1976:xi)

The PLISSIT model has been endorsed by the Royal College of Nursing (2000) and has been advocated for use in a wide range of clinical settings including dialysis (Gender 1999), cardiology (Seidl et al 1991), neurology (Nolan and Nolan 1998), oncology (Hughes 2000; Smith 1989; Smith and Babaian 1992), palliative care (Gamlin 2005) and rehabilitation (Goddard 1988; Hodge 1995). Despite being widely recommended, there is insufficient evidence of its value in practice.

One study that has been done was undertaken in Turkey. Ayaz and Kubilay (2009) conducted a randomised controlled study with 60 patients who had newly formed stomas. The intervention group of patients and partners received eight home visits (over a four-month period) from healthcare professionals using an intervention plan based on PLISSIT. Pre-test and post-test sexual function in the two groups was compared using the Golombok-Rust Inventory of Sexual Satisfaction (GRISS⁶⁴) (Rust and Golombok 2007). The study found significant improvement in overall GRISS scores in the intervention group, reporting improvements in sexual frequency and satisfaction ($p < 0.05$ ⁶⁵). Interestingly, although all couples shared a bed prior to surgery, only 20% of the intervention group and 18.3% of the control group slept with their partners on discharge from hospital. Those sharing a bed with their partner at the end of the four month period increased to 93.3% of the intervention group, but only 53.3% of the control group. This finding confirms the

⁶³ For example by providing information about human anatomy, and confirming that their sexual practices and fantasies are normal.

⁶⁴ The GRISS score includes measures relating to sexual interest and frequency, sexual dysfunction and sexual satisfaction.

⁶⁵ The authors did not provide details of the specific p values for these elements.

importance of addressing issues that are of concern to individuals, and not merely focusing on sexual performance. Concerns about odour, flatus and leakage from the stoma significantly impacted on the coupled relationship and influenced their separate sleeping arrangements.

Despite its apparent value in Ayaz and Kubilay's (2009) study, the PLISSIT model has been criticised because it is often interpreted to involve a linear, one-way process in which the patient is a passive recipient of healthcare (Davis and Taylor 2006). There is also the likelihood that permission to talk about issues or concerns is bypassed when professionals merely provide limited information (Davis and Taylor 2006). The extended version, Ex-PLISSIT, has explicit "permission-giving at its core" (Davis and Taylor 2006:112). Using this model, healthcare professionals are expected to make explicit to patients that it is appropriate to discuss any concerns they have about sexuality. Only if patients are able to voice their concerns can information and suggestions be tailored to meet their individual needs (Taylor and Davis 2006). Without being given explicit opportunities to discuss any concerns related to sexuality, patients may interpret professionals' silence as confirmation that this is not an appropriate topic for discussion (Taylor and Davis 2007). Recognising that people may not feel able to disclose all of their concerns at any one time, this model also requires healthcare professionals to review earlier conversations through further explicit permission-giving (Davis and Taylor 2006). Finally, healthcare professionals are encouraged to reflect on each interaction in order to increase their knowledge, self-awareness and understanding, challenging assumptions in the process (Davis and Taylor 2006).

Other models for addressing sexuality in healthcare practice include ALARM (Andersen 1990), BETTER (Mick et al 2004), and BLISS (de Vocht 2011). The ALARM acronym stands for **A**ctivity, **L**ibido, **A**rousal / orgasm, **R**esolution / release, **M**edical history (Andersen 1990). This model reflects the physiological sexual response cycle (Masters and Johnson 1966) and is a diagnostic tool that is limited by its biomedical approach. Its functional focus reinforces sexuality as a genital matter (Hordern 2008), and is reductionist in its approach.

Like the ALARM model, The BETTER model, was developed for use with patients with cancer. This model urges healthcare professionals to:

- **Bring up the topic.**
- **Explain you are concerned with quality-of-life issues, including sexuality ...**
- **Tell patients that you will find appropriate resources to address their concerns.**
- **Timing might not seem appropriate now, but acknowledge that they can ask for information at any time.**
- **Educate patients about the side effects of their cancer treatments.**
- **Record your assessment and interventions in patients' medical records.**

(Mick et al 2004:85)

Hordern (2008) suggested this model is an improvement on PLISSIT (Annon 1976) because it recognises sexuality as a quality of life issue and recognises that the timing of information should be based on individual needs. However, like PLISSIT, its focus is on educating and informing patients. For people anticipating or experiencing an end to their sexual life, the opportunity to tell their story and grieve their loss might be all that is required. Permission-giving involves creating a therapeutic space in which individuals can understand their experiences (Irwin 2000) and grieve any loss (Summerville and McKenna 1998) they have experienced. It also recognises that, in giving patients permission to discuss sexuality, they are also given permission not to talk about it (Taylor and Davis 2006).

Marsden and Botell (2010) undertook a study in which they used the Ex-PLISSIT model (Davis and Taylor 2006) as a framework for reflecting on conversations with patients attending a motor neurone disease clinic. This specialist nurse and registrar created a scoring system to record in the patients' notes when they had been given permission, limited information, specific suggestions, had been referred on for intensive therapy, and had been provided opportunities for review. At the end of two months they were disappointed to find they had not broached the subject of sexuality once. Having previously believed that they were comfortable with this topic, Marsden and Botell (2010) reflected that their input might have previously been reactive, rather than proactive. Indeed, opening the conversation is more difficult than the conversation itself (Hautamaki et al 2007).

Using the Ex-PLISSIT model (Davis and Taylor 2006) to reflect on the challenges they experienced in broaching the subject of sexuality, Marsden and Botell (2010) developed a strategy for improving their practice in this area. They routinely assessed every patient at their clinic appointment using the Amyotrophic Lateral Sclerosis Functional Rating Scale⁶⁶ (ALSFRS) (Haverkamp et al 1995), so decided to use the question about ‘turning in bed’ as a ‘trigger question’, which they followed by asking a question which gave people permission to discuss sexuality. This proved very successful, and they found over the next four months of the study period that no-one was offended that the subject had been raised. Indeed, many people were glad of the opportunity to talk about their sexual relationship.

The more recent BLISS communication model (de Vocht 2011) has been developed following research with patients and partners with cancer in the Netherlands. This model requires the practitioner to:

Bring up the topic in an appropriate way

Listen actively to the Individual experience

Support the individual

Stimulate communication between partners

Supply personalised advice and information; where necessary, refer to a specialised professional

(de Vocht 2011:99)

Like the Ex-PLISSIT model (Davis and Taylor 2006), BLISS recognises that people should be given the *option* to discuss sexuality and intimacy. In her study, de Vocht (2011:99) encountered patients who had not taken the opportunity to talk about sexuality and intimacy when given the opportunity, but:

... still appreciated the gesture, because it made them feel acknowledged as a sexual being by the health care professional.

The BLISS communication model has a greater emphasis on listening to the client’s experience than previous models. It is described as “support-focused instead of solution-

⁶⁶ The ALSFRS is a series of questions to assess functional changes and disability in people with MND (Haverkamp et al 1995). This tool is used to assess how much assistance individuals need with activities such as walking, turning in bed, and dressing; other elements focus on symptoms such as speech and salivation.

focused” (de Vocht 2011:1000), and emphasises the importance of empathy and enabling people to express their feelings. The BLISS model is consistent with a hermeneutic approach in its recognition that, by enabling people to tell their story, new understanding may emerge (van Manen 1990). The model also stresses the value of stimulating conversations between partners, which is an aspect previously unrecognised in any of the other models.

However, a model alone will not enable healthcare professionals to open up conversations with patients or partners. Indeed, the two studies that have been done to test two of the models in healthcare practice (Ayaz and Kubilay 2009; Marsden and Botell 2010) were used by practitioners already motivated to address sexuality with their client group. The value of models for healthcare professionals who are reticent to raise the subject is questionable.

Conclusion

By shifting our gaze from individuals living with a life-limiting illness to that of healthcare professionals brings us in a circle back to the experiences of the individuals themselves, and how their experience might be influenced or shaped by the professionals involved in their care.

The participants in this study did not have experiences of speaking about sexuality and intimacy with the healthcare professionals involved in their care. They have suggested that there is a place for these conversations, and require healthcare professionals to take the initiative by providing explicit opportunities.

When supporting patients and partners of patients with a life-limiting illness who experience disconnecting in their coupled relationship, it is important that their loss is recognised and acknowledged. Within a coupled relationship, the loss of a sexual relationship is disenfranchised when one partner does not recognise or validate the loss. This loss is further disenfranchised within a healthcare system that does not speak of sexuality or intimacy, or the effect of a life-limiting illness on the coupled relationship.

The beliefs, feelings and attitudes that healthcare professionals hold about sexuality and intimacy influence their approach to discussing this topic with patients. Healthcare professionals need to recognise that supporting coupled relationships is a legitimate and

important area of practice. They need to explore their own attitudes and reticence in broaching these conversations, and develop skills and confidence if they are to enable individuals to talk about their experiences and prevent their loss from becoming disenfranchised.

Before concluding this study with suggestions for healthcare practice, the following chapter reflects on the challenges I experienced in conducting this research, and discusses some of the lessons I have learned as a researcher.

Chapter 10: Challenges experienced and lessons learned

Introduction

Because I have contributed to the creation of data (Lowes and Prowse 2001; Wimpenny and Gass 2000), it is important that I am honest about my “failures and weaknesses” (Morse 2001:4). This chapter discusses the challenges I experienced in recruiting participants, gathering and analysing the data, and in maintaining safety for those involved.

Recruitment difficulties

It was extremely time-consuming building and maintaining relationships with staff who were recruiting. Whenever possible, I attended the weekly multi-disciplinary team meeting at one hospice, and so was able to ask, ‘Does this person meet my inclusion and exclusion criteria?’ I maintained telephone or email contact with other staff as a means of maintaining the study’s profile in their working lives and to address any difficulties that they encountered. I worked closely with them to ensure that a broad range of individuals were invited in order to achieve maximum variation in the sample.

I had anticipated recruiting through one MND clinic and two hospices. However, as recruiting patients and partners of patients with cancer was so slow, I obtained approval to use a third hospice. This proved more successful. In total, there were more than 25 members of staff that were involved in recruitment across the four settings. Although, in conversation, they were interested in and supportive of my study, their reticence in mentioning the study to prospective participants suggests a degree of ambivalence. This may, in part, have been influenced by knowing that there were many others involved in recruitment, as this diluted each person’s individual responsibility. However, their ambivalence was influenced by several other factors.

Many of these professionals avoided mentioning the study to people on their caseload because of their wish to protect patients. According to Fine (2003), paternalism is a matter of concern in research with patients nearing end of life. Acting in what professionals perceive to be the patient’s ‘best interests’ results in protectionism, which compromises people’s autonomy by not providing them with opportunities to make their own decisions

(Addington-Hall 2005; Alexander 2010; Boulton 2009; Cutcliffe 2002). The desire to protect patients has been found in other research with this population (Addington-Hall 2002; Chapple 2006; Corner and Clark 2002; Davies et al 1995; Ewing et al 2004; Wasow 1977), and was apparent in this study where professionals, acting in what they believed were the 'best interests' of patients, avoided inviting people to participate because it would, in their view, be too burdensome. Staff were required to exclude those that were not well enough to take part, but were also protective of those they considered to be experiencing distress (Addington-Hall 2002; Ewing et al 2004) or, as they frequently said, had "too much to deal with at the moment". This suggests that these professionals viewed participation as an unnecessary burden (Addington-Hall 2007; Davies et al 1995; Wasow 1977).

The sensitivity of sexuality and professionals' perception of its relevance for people proved another stumbling block. For example, one nurse considered it "inappropriate" to mention the study to a (married) vicar, and many of the recruiting professionals deemed the topic "not relevant" for many on their caseload. I was unclear what criteria they used to assess relevance.

Some staff spoke of being embarrassed to mention this sensitive subject (Seymour et al 2005), so it is feasible that the protection afforded to patients might also have been a way of staff protecting themselves. These factors combined to create a degree of selectivity by some of the recruiting staff, and might have influenced their perceptions of relevance.

As research was beyond their usual range of topics to discuss with patients, staff also reported forgetting to mention the study to patients. On other occasions, they considered that the consultation had been "difficult" for the patient (e.g. discussing a change in their medical condition, or problematic symptoms), and so had not felt research participation appropriate to broach.

In addition to these problems of gate-keeping, there were further difficulties in recruiting partners of patients. Although it was possible to invite some partners directly (when they themselves were receiving care), most partners' details were only accessible via patients' details, so could only be invited to participate via patients. Once the target numbers for patients had been reached, I considered it inappropriate to ask patients to give an invitation letter to their partner, whilst stating that they themselves were ineligible. This resulted in a need to recruit more patients than originally anticipated, and required ethical

approval of a substantial amendment to attempt to increase the numbers of partners of patients with cancer (Appendix 9).

Interestingly, it proved more difficult to recruit partners of people with cancer. While patients might have had a greater desire to help others or 'give something back' (the main reasons people gave for participation), the disparity between the number of couples with cancer and the number with MND was of concern. In the motor neurone disease clinic, patients and partners tended to be seen together, so both were present when the nurse explained the nature and purpose of the study. In contrast, patients with cancer were mostly invited when seen alone in day hospice or in-patient settings. Therefore, the intermediary's explanation and validation of the study might have been an influential factor in partners' participation because partners of patients with cancer were less likely to hear this, and were, therefore, totally reliant upon the patient's interpretation and the written information sheet.

This was not the only difficulty in recruiting partners. Because of their work commitments, partners of working age will have had less free time available for research participation. As one man who chose not to participate explained:

With my working hours I don't think it would be possible to complete this study ...
and I do not wish to give my weekends up.

This suggests that the burden of participation was prohibitive for partners who were working, and might have been reduced if the study's design used only one interview.

Despite attempts to recruit people from different ethnic backgrounds, the population from which staff were recruiting was homogenous. It was difficult to recruit people who were not heterosexual because the recruiting staff from these organisations reported only having heterosexuals on their caseloads. Indeed, the bisexual man who did take part had not disclosed his sexual identity to any healthcare professionals⁶⁷.

A further limitation in the sample was the missing voice of the dying. Of the 27 patients who took part, four died within three months of their last interview (Table 1). The exclusion criteria specified excluding those who were not considered well enough to take part and,

⁶⁷ This is consistent with the findings of research by Boehmer and Case (2004).

while necessary to avoid undue burden to participants, it is a subjective and variable criteria.

Overcoming recruitment difficulties

In order to improve recruitment, I attached the envelope containing the invitation letter and information sheets to the notes of all new patients attending the out-patient clinic at one hospice as a means of reminding staff. However, this strategy proved insufficient in overcoming the other difficulties described here.

The length of the invitation letter and information sheet might have been prohibitive. This was raised by individuals from affected communities who reviewed the paperwork before submission to the ethics committees. However, because of the requirement of the ethics committee, it remained lengthy. Terry et al (2006) found that hospice patients preferred verbal information rather than written information about a study:

Do not hand out a one and a half page brochure. There is a lot more to be done than that.

I don't think even my daughter would read that. No, really, sit with you and tell you.

(Terry et al 2006:411)

Citing these findings showing the burden to patients of lengthy written information sheets (Pleschberger et al 2011) might have enabled a more creative approach to recruitment to have been accepted by the ethics committee.

Before staff began recruiting, I discussed suggestions of how they could broach the research study with patients. I maintained regular contact throughout the recruitment period to offer support and to trouble-shoot any difficulties they voiced. Because this did not significantly increase recruitment, I submitted a substantial amendment to the ethics committee so that, if I was present in the clinic or at the hospice when staff were recruiting, individuals would have an opportunity to meet me so that I could explain more about the study and answer any questions they might have. This was approved (Appendix 7), and proved much more effective as a recruitment strategy. Partly, perhaps, because people could determine if I was someone they would wish to talk to, and also because the verbal explanation meant they were not solely reliant upon written information.

Given the difficulties that arose through gate-keeping, it would have been useful to involve staff earlier in the research process so that they appreciated the value of the study (Addington-Hall 2005; Ewing et al 2004). Similarly, it might have been useful before the study began to present these staff with research findings that show the value of research participation for people whose life is limited (Bellamy et al 2011; Terry et al 2006).

Although the purpose of research is not a therapeutic one (Lowe and Gill 2006), it is increasingly recognised that research participation can be beneficial for those involved (Bellamy et al 2011; Colbourne and Sque 2005; Cutcliffe 2002; Dyregrov 2004; Kvale 1996; Murray 2003; Romanoff 2001). Taking part can provide an opportunity for those who want to help others or to give something back (Addington-Hall 2005; Bellamy et al 2011; Cutcliffe 2002; Davies et al 1998; Terry et al 2006; Wilkie 2001).

Several of the participants in this study described wanting to give something back:

I was asked by [name of hospice] and they are so amazing that I thought I would do anything I could to help them.

(Dora)

However, most participants gave altruistic reasons for taking part:

Unless people give their experiences, no-one's going to know how to treat, or how they feel, or how to deal with it.

(Maureen)

... if in just one small little way it did help, then you feel you've done your bit.

(Sally)

If it changes one professional's attitude to it, and makes one person's experience better, than it's got to be worth doing, hasn't it.

(Sean)

The above quotes show that both patients and partners wanted to help individuals in similar circumstances to themselves. Others described wanting to support education:

I've been talking to you because we know you're doing a PhD and we wanted to help you.

(Cheryl)

These examples show that taking part in research can provide individuals with a "sense of purpose" (Fine 2003:s58; Hutchinson et al 1994:161), and a feeling that they have made a contribution. If recruiting staff were aware of these benefits, it might have provided balance to their concerns that people had "too much to deal with".

Research participation can also be cathartic (Alexander 2010; Beck 2005; Carpenter 1998; Hutchinson et al 1994; Lee 1993; Murray 2003) even if it involves strong emotions (Cutcliffe and Ramcharan 2002; Lowes and Gill 2006). Cook and Bosley (1995) found that bereaved adults described their experience of participating in research interviews as a positive one, even though some also found it emotional. Research interviews provide opportunities for participants to tell their stories (Alexander 2010; Atkinson 2002; Dyregrov 2004) and, in so doing, "off-load" (Lowes and Gill 2006:591) and gain insight into their experiences (Beck 2005; Cook and Bosley 1995; Morse 2002; Murray 2003). Research participation provides opportunities to discuss unresolved issues (Dickson-Swift et al 2008), and some people reach new understanding (Carpenter 1998; Thomas and Pollio 2002).

This was possible because understanding is a reciprocal arrangement (Hekman 1983). The research conversation was described by Kvale (1996:1) as an 'inter view' because both the researcher and participants may reach new understanding. This fusion of perspectives (Koch 1996) embraces Heidegger's (1962) concept of Dasein, of being open and awaiting the moment of understanding. The research interviews therefore provided participants with an opportunity to re-evaluate and make sense of their experiences. For some, this opportunity to reflect prompted a further conversation with their partner⁶⁸ (even if the partner did not take part in the study).

Human beings exist in the world as interpreters of experience (Heidegger 1962), and stories are re-shaped in their re-telling (Frank 1997; Romanoff 2001; Smythe 2011). Therefore, although research interviews are not intended to be therapeutic, they do provide participants with an opportunity to reflect upon and re-interpret their experiences.

⁶⁸ This has been exemplified in Chapter 9.

Although people's reasons for participation may be altruistic, there may also be personal gains in taking part (Dickson-Swift et al 2008).

To overcome the problems of gate-keeping, Ewing et al (2004) suggested greater collaboration between research teams and recruiting professionals. If I had been able to identify something that I could offer these professionals in return, their involvement in the study might have increased. Similarly, if the study topic related to an issue they were experiencing in practice, they might have felt an 'ownership' of the study and had a vested interest in its completion. In hindsight, it would have been useful to explore any concerns they had about discussing sexuality and intimacy with patients and their partners in more depth.

Reflections on interviewing

A number of issues presented themselves in gathering the data. This section presents my reflections on interviewing people who were very ill or lacked speech, my use of two interviews, and my role as researcher.

My role as researcher

The view of their world that people shared with me will have been influenced by a range of factors (Clarke 2003; Radley and Billig 1996; Wenger 2002). Whatever one person described in their interview shed light on their experiences, yet at the same time, also concealed their experiences. Heidegger (1962) described truth, '*aletheia*', as 'unconcealment'. Using this term demonstrates that when we reveal information, some remains concealed. This does not mean that people were lying when they described their experiences; merely that whilst some experiences were described, others were not. This will have been influenced by a range of factors.

Interviews occur in a gendered context (Arendell 1997; Williams and Heikes 1993), so using a male researcher with the male participants is likely to have found something different. However, it would not necessarily have been preferable for the men in this study to have been interviewed by a male researcher. Indeed, one man said after the interview, "I wouldn't have told a man all that I've told you". It would have been interesting to find out whether there were any specific examples he would not have disclosed to a man, but unfortunately I did not think to ask this.

Nurses who are also researchers can experience role conflict when collecting data, being drawn into giving information and advice (Carolan 2003). On the occasions when participants asked questions about their health or medication, I explained that I was unable to answer this, and suggested that they speak to their doctor or specialist nurse.

There were, however, advantages in my being a nurse as well as a researcher. My clinical experience in end of life care was also useful as I was familiar with the “physical manifestations” and difficulties people with life-limiting illnesses may face, and was alert to signs of deterioration or fatigue during the interviews (Addington-Hall 2005:89). Several participants referred to my ‘experience’ and this might have influenced their willingness to talk about this personal aspect of their lives.

However, there were occasions when I as a nurse was at odds with myself as a researcher. This became evident in one particular interview when Michelle had spoken about her guilt at having “sexual urges” even though her partner had not been dead many months:

As I said to you before, I feel a bit guilty sometimes because ... my sexual urges have come back. I've got no urge to fall in love, I've got no urge to meet a man and settle down but I have got urges, you know, and I feel bad because I think with Dave swanning around the place [as a ghost] (laughs). He can see me thinking these things, you know, it's really awful (eyes fill with tears) but I hope if he is around that he knows that I love him and I haven't got the need for anything, for any man in my life, I don't want to fall in love with anybody else, I'd want him 10 times over. You know you have these, see how I'm talking? It's terrible the effect it has on you. Wanting to have someone around, yet feeling guilty.

I responded:

But that's a natural feeling, just like the sexual urges are natural ones and, if it had been you that had died and Dave that had lived, he would still have had sexual urges.

Here I had strayed from data collecting to offering reassurances. While empathy is crucial when interviewing on sensitive issues (Dickson-Swift et al 2008), there is a fine balance between compassion, maintaining concern for people's well-being, and therapeutic intent. The conflict here was whether beneficence should take precedence over the research

imperative (Munhall 2007). I was aware of this during this interview and made a deliberate choice to respond in a therapeutic manner because Michelle had returned to the feelings of guilt she had previously described. My concern was that, by not acting as I did, I might have compounded her sense of guilt. I discussed this transition between collecting data and therapeutic intervention with my supervisors afterwards, and was reassured that my role as data collector was not overshadowed by any comments I made as a 'nurse'.

Nonetheless, it is important to recognise the part I played in gathering people's stories. My gender, age, comfort and experience with the subject matter all influenced what people shared. The questions that I asked (and didn't ask), and how I responded to participants' disclosure all contributed to a shared construction of the data (Lowes and Prowse 2001). It was *in conversation* (both verbal and non-verbal), that these stories were gathered.

Using more than one interview

Many researchers recommend more than one interview for phenomenological studies (Clarke 2003; Kahn 2000), suggesting that this enhances rapport (Clarke 2003; Lee 1993). Cotterill (1992) found much greater 'impression management' (Goffman 1990) in the first interview than subsequent ones, suggesting that participants abide by "culturally defined rules for appropriate behaviour between strangers" (Cotterill 1992:595) and only move from "public to private accounts" (Cotterill 1992:596) in subsequent interviews once trust and rapport have developed. However, in my study I found that participants rarely offered new experiences in the second interview, suggesting that rapport was not reliant upon more than one interaction. It is feasible that my presentation in the information sheet as a nurse and the endorsement provided by the recruiting professionals facilitated trust and greater disclosure.

It is notable that some of the second interviews which did elicit previously unmentioned experiences were pivotal in my analysis. Without Frances' description of re-connecting with her husband (this occurred as a consequence of telling me about their relationship in the first interview⁶⁹), my understanding of the potential for re-connecting would have remained limited.

⁶⁹ This is discussed in Chapter 9 under the heading '*Experiences of talking about sexuality and intimacy in the research interviews*'.

The second interviews also proved useful because they provided opportunities for further exploration of issues, which often resulted in richer description. Furthermore, knowing that there would be a second opportunity to explore issues meant that I sometimes made a conscious decision in the first interview to save a question until the second interview. I did this with people who were very ill, or when participants indicated that the interview could take no longer than the suggested time because they had other commitments.

Interestingly, one of the participants also made use of the intervening time between the first and second interview. Having chosen not to share something with me in the first interview, he sought the permission of his extra-dyadic sexual partner before revealing and describing their relationship in the second interview. His discussion of this relationship (which ended before he was diagnosed) played a key role in enabling me to understand the phenomena of connecting and disconnecting⁷⁰.

On reflection, although interviewing participants twice did prove useful in this study, the burden of participation should not be underestimated (Hutchinson et al 1994).

Interviewing people without speech

One of the exclusion criteria for recruitment was 'individuals who do not speak English'. However, there is a high prevalence of aphasia in people with MND (Talbot et al 2010), and a review of published work from 1980 to 2005 has shown that people with expressive language difficulties are frequently excluded from research (Lloyd et al 2006). The practitioner recruiting from the MND clinic asked me for further clarification, wondering whether she should invite people who used electronic speech-assistive devices. I considered it important to include this group in order to give people a 'voice', so confirmed that this would be appropriate and that she could reassure prospective individuals if they themselves were unsure of their eligibility.

However, one such patient opted not to use the computer when I arrived at his house, despite having agreed in our previous email correspondence that he could use the 'voice' software on his computer. He indicated that he would use an alphabet board instead. I was unnerved by this change to our agreement and unsure whether I would be able to gather sufficient data. However, I needed to think on my feet and didn't want to disempower him by doubting his assurance that it would be 'alright', so agreed.

⁷⁰ This is illustrated later in this chapter with extracts from my reflective journal.

I still audio-recorded this interview so that I could capture my questions and comments, and agreed with him that I would verbalise the letters he pointed to in order to show that I understood, as well as record his responses. The interview proved painstakingly slow, and appeared to be an effort for him (Clarke 1999). After pointing out two or three letters, he would look up at me to see if I had understood. I considered it unfair to pretend not to know what he was saying if I did have an idea, as this would tire him further, so asked him if he wanted me to complete the words for him. He affirmed this.

Cooper and Guillebaud (1999:73) discussed the challenge for counsellors in working with people with limited speech and suggested offering “guestimates”, which the participant could accept or reject. This had not been my intention when embarking on the interviews, but seemed at the time the best solution, and one that he certainly wanted. We therefore agreed that I would verbalise what I thought he was saying and that he would confirm or correct my interpretations (Clarke 1999). He did this by shaking his head or uttering what I interpreted to be a despairing noise when I got it wrong, and nodded with his thumb up when I was correct. In some situations, this would raise concerns about interpretation bias (Lloyd et al 2006), but this was not an issue in this case because he was very clear what he was ‘saying’ and freely corrected me when I misinterpreted his words.

The data from this interview proved less useful than others because of the very limited narrative, but nonetheless provided useful insights into the experiences of someone with profound disabilities. In hindsight, it would have been helpful if I had ascertained why he did not want to use the computer. If, for example, it was in need of repair, I could have rearranged the interview for a more suitable time.

It is important not to exclude people with speech impairments from research to avoid further disempowerment (Lloyd et al 2006) and to learn from their experiences. This would need greater creativity in designing data collection methods to enable people to express themselves as much as they are able (Lloyd et al 2006). Including a speech and language therapist or occupational therapist on the research team could facilitate this, as well as learning from the experiences of other researchers.

Interviewing people who were very ill

I experienced conflicting thoughts and emotions when interviewing participants who were clearly very ill, and found it helpful to record my reactions in my reflective journal (Murray 2003):

How easy is it for people to refuse once they've said they will take part? I asked Jim if he wanted to stop on a couple of occasions during the interview, yet he wanted to carry on. I always reiterate before and during the interview that if there are any questions people don't wish to answer, they don't have to. However, it's not so easy for them to do this with a direct question. I'm sensitive to people's feelings and am not uncomfortable when they express their sadness. However, I want to be sure that I am not compounding this by prompting their thinking in areas they've not considered. It's such a fine balance when researching such a sensitive issue; how will I know if I've avoided harm?

Given my concern at compounding distress, I was heartened when one participant said, "that's one question I ain't answering". This was not, to my surprise, a question about sexuality or intimacy, but about whether the doctors had spoken of a prognosis. This was something that she was not prepared to discuss, perhaps because saying aloud how long she was expected to live might make it more 'real'.

People's willingness to talk also posed other challenges, as shown in my reflections on interviewing Kathleen:

Kathleen had forgotten I was coming today. I was struck with how less well she seemed than when I met her at the hospice 10 days ago. It was no later in the day, so I wondered whether the morphine had been increased and was making her very sleepy. She said she was "less well" and I wasn't sure what she meant by this. Did she feel she was nearing the end? I myself wondered whether she might be entering the dying phase; thinking and talking seemed such an effort for her, and she was finding it hard to stay awake.

Was it right to proceed with the interview? I asked myself this many times in the short time I was there. Because she said, wistfully, "I so wanted to help", I decided that it was appropriate. She was able to provide consent, so I began, but was able to get very little narrative from her. After only 13 minutes, I called the interview to a stop because she was having difficulty concentrating and it was such an effort for her to stay awake. It didn't feel right to tell her this, so I told her that what she'd said had been very helpful. I felt she had so much invested in wanting to help, that it would be unethical to deny her the feeling that she had contributed. In fact, she had

helped. It was clearly so important to want to take part. Her exhausted, ill state provided emphasis to the few words she did speak.

Kathleen died 15 days after this interview.

Not permitting people to participate would have been harmful (Chapple 2006) by compromising their autonomy (Ewing et al 2004). However, continuing without the possibility of useful data would not have been morally justified. As a researcher, I paid careful attention to the balance between benefit and harm. This would have been more challenging if this study had specifically sought the views of people in the last three months of life.

Maintaining safety for the research team

The potential for harm to me as researcher

In addition to avoiding harm to participants, it was also important to consider the potential risks to myself (Dickson-Swift et al 2007). The location of interviews felt more of a challenge when arranging interviews with men (Arendell 1997), because I was much more aware of issues of personal safety. I carried a mobile 'phone (McCosker et al 2001) for all interviews, and gave a sealed envelope with the name, address and telephone number of where I was interviewing and the time I expected to finish (McCosker et al 2001) to a person designated by my supervisors. I contacted them when I had finished each interview, and they were instructed to shred the contact details.

I was aware that my ease with talking about sexuality, and my empathetic responses to participants' experiences, might potentially be misconstrued by some as an invitation or 'come on'. This was particularly evident in the second interview with one man. I was uncomfortable during his detailed descriptions of his extra-dyadic sexual relationship and his earlier loss of virginity and doubted the relevance of these stories. My conflicting feelings are evident in my journal entry following this interview:

It seemed that he was trying to establish some sort of sexual bond with me. When talking of his sexual exploits before his diagnosis (adultery and losing virginity) he didn't appear embarrassed. He looked directly at me the whole time, with eyes bright. Was he gleeful? Lascivious? I felt very uncomfortable and was concerned about my safety.

While he was telling me about his sexual relationship with the other woman, a number of thoughts and feelings crossed my mind:

- I was bored by the detail he was going into. Why was he telling me all this? It happened before he was diagnosed. What were his motives in telling me?
- I couldn't imagine anyone wanting to have sex with him.
- I felt for his wife ... It seemed so callous to blame it all on her. How cowardly, to blame her rather than take responsibility himself. I wonder what the impact was on her? Does she feel safe within their marriage? I am outraged at the pain he is likely to have caused her.
- The door was just behind me, but I couldn't remember how he locked it. If I was in danger, how would I exit? What would I say? Should I remain polite? After all, I am a representative of the university as a research student.

While all this was going through my mind, I tried to maintain a passive, attentive face. I was conscious of not laughing, smiling encouragingly or even licking my lips (as it may be misconstrued as a sexual invitation).

He said he'd found it helpful to talk. Of course he did. I sat there nodding while he told me of his adultery. He said he'd not been able to tell anyone else and that he felt much better. It's unlikely that a friend or family member would have sat nodding, not showing shock or judging him. No wonder he felt better talking to me. Did he feel he'd expunged some of his guilt? I certainly feel, in some way, complicit in his adultery. By nodding and not reacting, my responses suggested that his behaviour was acceptable, that I approved.

It is evident from this journal entry that I was unsure how to respond in a way that ensured my safety, retained rapport and would enable us both to 'save face', especially if I had misinterpreted his actions. Thankfully, the moment passed when he moved on to another topic and my concerns about safety subsided.

It is not always possible at the time to know if an interview is productive (Thomas and Pollio 2002). Listening requires the researcher to attend to "the dominant and the muted meanings" (Kavanagh 2007:9), and I was sufficiently aware not to discount this human

experience (Drew 1989). Through further writing, I became more aware of my 'prejudices' (Clarke 1999) and the influence of these pre-suppositions on my interpretations:

I feel antipathy towards him as a sexual being and wonder if his wife has felt the same? I wonder if his descriptions of what I think of as 'irrelevant' experiences will prove to be a turning point in my analysis?

I recognised that my analysis would be influenced by my emotional responses (Mauthner and Doucet 2003), and it was only after I had processed my feelings about this interview, that I was able to understand the significance of this participant's descriptions. It was through trying to understand the meaning that these other sexual experiences held for him, and their relevance when he knew he was dying, that enabled me to see for the first time the 'connection' he missed within his marriage and found in his extra-dyadic relationship.

If I had been unable to process my mixture of emotions, it is likely that I would have dismissed the relevance of these experiences, which would not have been consistent with Heideggerian philosophy (Lowes and Prowse 2001). As I had rightly surmised, his interview was a turning point in my thinking. Reflecting on how I responded in this situation made me better prepared for other challenging scenarios and highlighted for me the value of my reflective journal.

In emotionally-laden research, the researcher is vulnerable to harm (Cotterill 1992; Dickson-Swift et al 2008; Liamputtong 2007) because s/he is tasked with "trying to understand the experience without sharing it" (Morse 2000:540). Research on sensitive issues can be emotionally draining (Liamputtong 2007; Pleschberger et al 2011) and can affect partnered relationships (McCosker et al 2001). Although some of the stories did cause me to reflect upon my own relationship, wondering how it might be affected if we were faced with similar illnesses, this was not at any personal cost. The reason I wasn't emotionally drained by the interviews is, in part, because recruitment was sporadic and therefore the cumulative effect of interviews was reduced. I believe a major factor was my familiarity with sexuality and extensive experience nursing people and supporting families facing end of life. This is not to say I was untouched, but I was able to process the feelings generated and recognise that it was their pain rather than my own.

What I had not anticipated, however, was that some of the interviews might trigger memories of our daughter before she died. Because she was only nine and I was

interviewing adults, it had not occurred to me that this might happen, as shown in the following extracts from my journal:

Reflection following first interview with Maria

When I asked about hair loss, I was taken aback when she suddenly removed her wig ... It 'sat' on her lap for the remainder of the interview, like a cat. She didn't sit and stroke it, but I wouldn't have been surprised if she had ... The shock I felt when she removed her wig was instantly 'seeing' Martha: very sick, with patchy hair that was growing back, cheek bones submerged in puffiness, and lots of facial hair. Until Maria removed her wig (which had a fringe), the puffiness of her face wasn't very evident. Without her wig, however, I got an impression of what her face might have looked like before the steroids. I felt I needed to keep a check on my reaction. Not that I was upset by the unsuspected reminder of Martha, but I was distracted and needed to work hard to concentrate on Maria and what she was saying. I found that it helped to look at her mouth, not her eyes or her whole face. What a relief when she put the wig back on at the end of the interview! Suddenly she became Maria again, and not a reminder of Martha.

Reflection following second interview with Maria

Again, Maria took her wig off part way through the interview (when she spoke about her hair). There was no warning. Her hand went up to her head and, in a flash, her wig was off. It was much easier this time for me as I knew the memories it might trigger, and so thankfully it didn't have the same distracting effect as last time.

It was helpful after this interview to have time to reflect. Experienced qualitative researchers recommend having strategies in place to support them when dealing with emotive research (Davies et al 1995; Dickson-Swift et al 2007; Gabb 2010; Lee 1993; Lowes and Gill 2006; McCosker et al 2001; Pleschberger et al 2011). I did not establish any formal support mechanisms, but was aware of opportunities for peer support within my workplace, should I need it. Journaling my feelings proved a valuable way of processing them and maintaining my emotional safety (Malacrida 2007), as well as heightening my self-awareness (Smith 1999).

The potential for harm to transcribers

What I hadn't given sufficient thought to in advance, was the emotional effect on the transcribers, for they too were at risk of emotional harm (Dickson-Swift et al 2008; Gregory et al 1997; McCosker et al 2001; Sheldon and Sargeant 2007) and somatised emotions (Morse and Mitcham 1997). Although I had explained the nature of the study to them beforehand, they explained that repeatedly listening to the audio-recordings increased the intensity of participants' stories (Gregory et al 1997) and evoked memories of their own. For example, one of the transcribers identified parallels with her own experience of caring for a dying relative. She managed this reaction by pacing the transcribing and limiting the time spent working on it in any one day. Because she shared her difficulty with me, I was able to support her strategy and did not expect the work in accordance with previously agreed deadlines. Once I was aware of the issues that resonated with her own experiences, I was able to highlight potentially 'challenging' interviews in advance and telephoned her to provide support and debrief after 'difficult' interviews (Dickson-Swift et al 2008; Gregory et al 1997).

Summary of this study's limitations

It is possible that people who agreed to take part in a study on sexuality and intimacy valued this aspect of their lives more than others who chose not to participate. However, as discussed above, most of the people who took part in this study described doing so for altruistic reasons and not because of the subject matter itself. It is therefore feasible, though not certain, that their experiences and understanding of sexuality and intimacy reflect the experiences of others.

Because sexuality and intimacy are sensitive subjects, the rich descriptions of experiences that one might normally expect to find in phenomenological research were much briefer in this study. I needed to use more prompts to encourage participants to talk about these personal aspects of their lives, so it is likely that further aspects of people's experiences remained hidden.

My intention had been to uncover shared meanings of sexuality and intimacy amongst people of all sexualities, but I was unfortunately only able to interview two people who did not describe themselves as heterosexual. Others who were under-represented are people from different ethnic backgrounds and those who rely on technology to communicate. Also,

because only four of the patient participants were interviewed in their last three months of life, the experiences of those nearing the end of their life have been under-explored.

Heideggerian hermeneutic phenomenology does not purport to uncover absolute truth, for with every revealing there is also concealing (Heidegger 1962). These stories have been gathered within the relational context of conversations with me as a researcher. As gatherer and interpreter of people's stories, my own fore-structures of understanding have influenced how I have come to interpret and understand these phenomena (Heidegger 1962). The interpretations I have made are not the only facet of people's experiences. It is likely that there are other interpretations that I have not uncovered.

Conclusion

In this chapter, I have discussed the recruitment challenges I faced and suggested strategies for overcoming issues of gate-keeping. I have also explored my role within the research interviews, and discussed my reactions and responses to several challenging situations. I have been aware of how my emotional reactions have influenced the study (Drew 1989), and have included them here to show how the data and interpretations have been co-constructed.

It is important to anticipate the emotional nature of research and anticipate its potential effects (Dickson-Swift et al 2008). Although I had anticipated, and prepared for, the emotional impact on participants, I had overlooked the effect on transcribers. In qualitative research, it is not possible to predict all the issues that could be raised, or how participants, researchers or transcribers will react. It is therefore important to be alert for distress and to have a range of support strategies in place.

As a researcher, if my work is to be trustworthy, I need to demonstrate how I have influenced the data generated, the conversation that has taken place. Although the intention of phenomenological researchers is that participants should take the lead in the interview conversation, it is important that I recognise when I myself have pointed out the path to take (whether deliberately or inadvertently).

Chapter 11: Conclusions

Say not, 'I have found the truth', but rather, 'I have found a truth'

(Khalil Gibran 1972:49)

The purpose of this study was to understand the lived experience of sexuality and intimacy for people living with a life-limiting illness. However, presentations of the findings from hermeneutic analysis are always tentative as they reflect the researcher's understandings at the time of writing. My interpretations are not 'findings' as such as there is no one truth, no one perspective, no one correct interpretation (Heidegger 1962); "every experience has layer upon layer of meaning embedded within it" (Smythe et al 2008:1391).

The 'findings' I have presented in this thesis are, therefore, what I have seen in the data that seemed to be of significance, things that have called to me and held my thinking. It is not possible to make fully explicit my pre-suppositions (Lavery 2003), but in using a Heideggerian, hermeneutic methodology I have attempted to demonstrate balanced integration and openness (de Witt and Ploeg 2006). I have endeavoured to ensure that my interpretations are credible by reflecting upon my experience as the gatherer and interpreter of people's stories (Koch 1996). In presenting my voice alongside that of the story-tellers, readers are able to judge for themselves whether the interpretations presented here resonate with their own experiences and awaken new understanding.

Although sexuality and sexual behaviour mean "different things to different people" (Ford and Beach 1952:2), this study has shown that these individuals who were living with a life-limiting illness held shared understandings and meanings about the role that sexuality and intimacy played in their lives. This study has provided insights into the human condition by shedding light on some of people's hitherto unspoken experiences.

The phenomenon is "that which shows itself from itself" (Heidegger 1962:51). My intention had been to study the phenomena of sexuality and intimacy. However, along the journey towards understanding I came to realise that the research question has been a door to phenomena I was previously unaware of, those of connecting, disconnecting and re-connecting in the being-in-the-world of coupled relationships.

In many ways, physical intimacy eludes the dying. In their being-towards-death-of-the-couple, participants experienced disconnecting from their partner. This becoming-apart-as-

a-couple was experienced as loss of spontaneity, as lack of reciprocity, as rejection, and as 'rights and duties'. It was influenced by a range of factors that included disfigurement, lack of privacy and the disabling effects of technology. Some participants, but no means all, described re-connecting as they experienced becoming-closer-as-a-couple.

My intention in embarking on this journey was to inform the lens through which healthcare professionals view the world of people living with a life-limiting illness. Despite the primary goal of palliative care being to improve quality of life (National Council of Hospice and Specialist Palliative Care Services 1993; Richards and Ramirez 1997), existing healthcare research has largely overlooked sexuality and intimacy in those who are dying. This study has shown that, for these participants facing death due to MND or cancer, sexuality and intimacy continued to be important in coupled relationships, regardless of people's age or gender.

A way forward

If 'holistic healthcare' is to move beyond rhetoric, healthcare professionals need to identify and respond to individuals' wishes and preferences (Department of Health 2008). This necessitates recognising individuals within the social context of their coupled relationship and acknowledging the effects that changes in the health of one or both partners has on that coupled relationship.

Suggestions for healthcare practice

Previous research has shown that people facing end of life emphasise the importance of meaning (Carter et al 2004; Cohen and Mount 1992; Noble and Jones 2005) and focus upon strengthening relationships and resolving 'unfinished business' (Clark 1990). However, it is important to recognise that people do not always want solutions (Irwin 2000), but might benefit from the opportunity to talk about their experiences (to gain insight) and to grieve any loss. If healthcare professionals acknowledge the loss that is experienced through disconnecting, individuals' experiences can be validated instead of disenfranchised. By providing opportunities for people to tell their relationship stories, healthcare professionals would legitimise discussion of sexuality and intimacy, and break the silence surrounding these hitherto taboo topics.

This study raises a number of questions that warrant further consideration in healthcare practice:

- ◆ Does the focus upon the individual and the family in hospice and palliative care overlook the coupled relationship?
- ◆ How can the culture of patient care facilitate connecting between partners?
- ◆ What can be learnt from the way healthcare professionals discuss emotive issues of death and loss with patients and their families that can inform the provision of care that supports sexuality and intimacy?
- ◆ What role do healthcare professionals have in supporting couples living in the twilight of their relationship?
- ◆ Do they have a role in enabling partners to communicate with each other?
- ◆ Do they have the necessary skills to facilitate this?
- ◆ What education do healthcare professionals need in order to develop these skills?

Because many of the participants in this study had lived with illness or disability for a number of years, it is reasonable to infer that the new understandings that have arisen might also be meaningful for people living with chronic illness or other incurable conditions. These individuals might also experience connecting and disconnecting in their coupled relationship as they live with chronic illness.

Ironside et al (2003:178) asked healthcare professionals to consider how they “attend to the meaning symptoms have for clients”. Unless professionals find a way of enabling conversations with patients and their partners who are living with a life-limiting illness, the silence surrounding sexuality will persist and these meanings will remain hidden. How then will healthcare professionals be able to provide care that is truly holistic and person-centred?

My own horizon of understanding as a palliative care nurse has expanded to incorporate the differing perspectives of the patients and partners who participated in this study. I had not previously considered ‘connecting’ as a phenomenon, though what I have learnt from these participants resonates with the pre-suppositions I described in Chapter 4. Since undertaking this study, my own nursing practice has changed. I now find myself talking with patients and their partners about ‘connecting as a couple’ rather than ‘sexuality’. This does not mean that I avoid mentioning sexual activity, and use ‘connecting’ as a catch-all term. Instead, I have come to understand ‘connecting’ as a relational experience, and

recognise that people may perceive 'sexuality' as only involving sexual experience. Using 'connecting as a couple' provides an open platform on which a variety of conversations can take place.

Although this study has found shared meaning in the experience of connecting, disconnecting and re-connecting, it continues to be important to recognise differences when providing individualised care.

Suggestions for education

If healthcare practice really is to be holistic, then sexuality and intimacy need to be explicit within educational curricula. The insights gained from this study are important to include in palliative care education in pre-qualifying and post-qualifying courses for a range of healthcare professionals including nurses, occupational therapists and doctors. Curricula should include not only the impact of changes in sexual function, but also the potential for disconnecting within the coupled relationship and consideration of professionals' role in supporting couples in the being-towards-death of their coupled relationship.

In reviewing the existing literature, I have shown that knowledge and models are insufficient in enabling healthcare professionals to address issues of sexuality and intimacy in practice. It is important that educational programmes enable students to explore their attitudes, values, beliefs, fears and concerns if practice is to change. In my own teaching, the new understandings gained from this study have enabled me to more effectively challenge the views of students who state that sexuality and intimacy are not matters of concern when people are facing end of life.

For healthcare professionals to feel comfortable and confident in discussing these issues with patients and their partners, it is important that communication skills training includes consideration of sexuality and intimacy. The language of connecting, disconnecting and re-connecting could facilitate this.

Suggestions for research

Although this thesis has revealed several different aspects of people's experiences, it is likely that there are other faces of this prism that remain to be uncovered. The voices of patients and partners of patients in in-patient units have been largely silent, and the experiences of people not in partnered relationships might further extend these understandings beyond the interpretations I have drawn.

In order to inform healthcare practice, this study raises a number of questions for further research:

- ◆ What are the experiences of gay men, lesbians and bisexuals who are facing end of life?
- ◆ What makes it possible for some couples to find new meaning and maintain connecting with their partner, and others to experience disconnecting?
- ◆ How do partners' experiences of connecting, disconnecting and re-connecting influence bereavement and adjustment?
- ◆ What are the needs of those who are not in a coupled relationship? How can these needs be met?

There is also a need for research that explores the perspective of healthcare professionals in order to further understand the barriers to conversations about sexuality and intimacy with people who are living with a life-limiting illness and facing end of life. Important questions for research include:

- ◆ What are the views and experiences of staff caring for people with life-limiting illnesses about addressing sexuality and intimacy with patients and their partners?
- ◆ What are the factors that enable and constrain these staff having conversations about sexuality and intimacy with those in their care?

There is also a need for further research to understand the experiences of people whose partner has died, in order to understand how they make sense of their being-in-the-world in the context of sexuality and intimacy. It is by understanding how people make sense of these experiences that hospice and palliative care services will be more able to meet the needs of the bereaved people they support. This could also increase our understanding of how best to support couples before death occurs.

The next step

Cooper and Guillebaud (1999) challenged the view that society discriminates against people with disabilities and does not recognise their sexual needs, arguing that it is you and I that make up that society. In undertaking this thesis, I was aware that the sexual needs of people with disabilities are not recognised within healthcare practice. However, I had not fully understood what these needs might be. I am hopeful that you, the reader, and I, will begin to challenge the views of others who do not recognise that sexuality and

intimacy can play an important part in the lives of people living with life-limiting illnesses, regardless of their age, disability or frailty.

I feel privileged that people have shared their experiences with me and feel a responsibility to continue to publish my interpretations in a way that audiences can relate to. So far, I have used a variety of ways of bringing the voices of participants 'alive' for academic audiences on study days and at conferences. These have included using pairs of shoes to represent both partners in a coupled relationship in order to challenge pre-conceived ideas and assumptions about the issues people with life-limiting illnesses experience in relation to sexuality and intimacy. My plan is to continue to disseminate the findings from this study by further conference presentations and publications in academic journals.

While healthcare professionals remain silent about these issues, it is not sufficient to only disseminate these findings to academic audiences. In addition to the leaflets that have so far been published (Marsden and Taylor 2012a; Marsden and Taylor 2012b), I am exploring ideas for a poster which will bring the study's findings about connecting and re-connecting to people from affected communities. This poster is intended for display in outpatient clinics and support groups.

Final words

The understanding that I have gained from undertaking this work brings with it a sense of seeing anew. However, the cyclical process of interpretation and understanding is never-ending, for understanding of what it is to be human is always 'on the way' (Heidegger 1962). In our never-ending circle of interpretation, the end is to go back to where we started:

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And to know the place for the first time.

(Eliot 2001b:43)

References

- Abraham J (1930) Introduction. In: van de Velde T, *Ideal Marriage: Its Physiology and Technique*. New York: Random House Inc., vii-viii.
- Adams J (2000) Sex and politics. In: Wilson S, McAndrew S (Eds.) *Sexual Health: Foundations for Practice*. Edinburgh: Baillière Tindall, Ch.2, 33-45.
- Adams J and Painter C (1995) *Sexuality*. Presented at Sexual Health in Primary Care Conference, London. 24th April.
- Addington-Hall J (2007) Introduction. In: Addington-Hall J, Bruera E, Higginson I, Payne S (2007) *Research Methods in Palliative Care*. Oxford: Oxford University Press, Ch.1, 1-9.
- Addington-Hall J (2005) Best practices in research methods: palliative care research in practice. *Canadian Journal of Nursing Research*, 37(2), 85-93.
- Addington-Hall J (2002) Research sensitivities to palliative care patients. *European Journal of Cancer Care*, 11(3), 220-224.
- African Palliative Care Association (2012) *The history of palliative care*. Available at: http://www.apca.org.ug/index.php?option=com_content&view=article&id=43&Itemid=28 (Accessed on 19th May 2012)
- Agich G (1995) Chronic illness and freedom. In: Toombs K, Barnard D, Carson R (Eds.) *Chronic Illness: From Experience to Policy*. Bloomington: Indiana University Press, Ch.7, 129-153.
- Ahmedzai S and Walsh T (2000) Palliative medicine and modern cancer care. *Seminars in Oncology*, 27(1), 1-6.
- Aitken A (2009) *Community Palliative Care: The Role of the Clinical Nurse Specialist*. Chichester: John Wiley and Sons Ltd.
- Alexander S (2010) 'As long as it helps somebody': why vulnerable people participate in research. *Journal of Palliative Nursing*, 16(4), 174-179.
- Allan G (1980) A note on interviewing spouses together. *Journal of Marriage and the Family*, 42(1), 205-210.

- Allen D (1995) Hermeneutics: philosophical traditions and nursing practice research. *Nursing Science Quarterly*, 8(4), 174-182.
- Allen J, Heyrman J, Gay B, Crebolder H, Svab I, Ram P, Deighan M, Field S, Fraser A, Thomas H, Hibble A (2007) *Royal College of General Practitioners Curriculum Statement 1: Being a General Practitioner*. London: Royal College of General Practitioners.
- Alty A and Rodham K (1998) The ouch! factor: problems in conducting sensitive research. *Qualitative Health Research*, 8(2), 275-282.
- American Cancer Society (2011) *Hospice Care*. Available at: <http://www.cancer.org/Treatment/FindingandPayingforTreatment/ChoosingYourTreatmentTeam/HospiceCare/hospice-care-what-is-hospice-care> (Accessed on 18th May 2012)
- Ananth H, Jones L, King M, Tookman A (2003) The impact of cancer on sexual function: a controlled study. *Palliative Medicine*, 17(2), 202-205.
- Andersen B (1990) How cancer affects sexual functioning. *Oncology*, 4(6), 81-88.
- Andrews M, Lyne P, Riley E (1996) Validity in qualitative health care research: an exploration of the impact of individual researcher perspectives within collaborative enquiry. *Journal of Advanced Nursing*, 23(3), 441-447.
- Anells M (1999) Evaluating phenomenology: usefulness, quality and philosophical foundations. *Nurse Researcher*, 6(3), 5-19.
- Annon J (1976) *Behavioural Treatment of Sexual Problems: Brief Therapy*. London: Harper and Row.
- Arendell T (1997) Reflections on the researcher-researched relationship: a woman interviewing men. *Qualitative Sociology*, 20(3), 341-368.
- Arthur L and Arthur T (2000) *Shadow in Tiger Country: One Last Year of Love*. London: Harper Collins Publishers.
- Askew J and Davey M (2004) Women living with men who use Viagra: an exploratory study. *Journal of Couple and Relationship Therapy*, 3(4), 23-41.
- Atkinson R (2002) The life story interview. In: Gubrium J, Holstein J (Eds.) *Handbook of Interview Research: Context and Method*. London: Sage Publications Ltd, Ch.66, 121-140.

- Attig T (2001) Relearning the world: making and finding meanings. In: Neimeyer R (Ed.) *Reconstruction of the Experience of Loss*. Washington: American Psychological Association, Ch.2, 33-53.
- Attig T (1996) *How we Grieve: Relearning the World*. Oxford: Oxford University Press.
- Avens S (1986) Love and death. *Nursing Times*, 82(35), 35-36.
- Ayaz S and Kubilay G (2009) Effectiveness of the PLISSIT model for solving the sexual problems of patients with stoma. *Journal of Clinical Nursing*, 18(1), 89-98.
- Baker C, Wuest J, Stern P (1992) Method slurring: the grounded theory / phenomenology example. *Journal of Advanced Nursing*, 17(11), 1355-1360.
- Barnes P (2009) *Wish 143*. British Broadcasting Corporation. Available at: <http://www.bbc.co.uk/filmnetwork/films/p00bjp8d> (Accessed on 4th June 2012)
- Barni S and Mondin R (1997) Sexual dysfunction in treated breast cancer patients. *Annals of Oncology*, 8(2), 149-153.
- Bauer M, McAuliffe L, Nay R (2007) Sexuality, health care and the older person: an overview of the literature. *International Journal of Older People Nursing*, 2(1), 63-68.
- Be All Films Ltd (2010) *The Be All and End All*. Be All Films Ltd. [DVD]
- Beauchamp T and Childress J (2001) *Principles of Biomedical Ethics* (5th edition). Oxford: Oxford University Press.
- Beck C (2005) Benefits of participating in internet interviews: women helping women. *Qualitative Health Research*, 15(3), 411-422.
- Becket F (2002) *The Complete Critical Guide to DH Lawrence*. London: Routledge.
- Bellamy G, Gott M, Frey R (2011) 'It's my pleasure?': the views of palliative care patients about being asked to participate in research. *Progress in Palliative Care*, 19(4), 159-164.
- Benner P (1994) The tradition and skill of interpretive phenomenology in studying health, illness and caring practices. In: Benner P (Ed.) *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness*. London: Sage Publications Ltd, Ch.6, 99-128.
- Benner P (1984) *From Novice to Expert*. London: Addison-Wesley Publishing Company.

- Béphage G (2008) Meeting the sexuality needs of older adults in care settings. *Nursing and Residential Care*, 10(9), 448-452.
- Berger P and Luckmann T (1966) *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. London: Penguin Books.
- Bergmak K, Avall-Lundqvist E, Dickman P, Henningsohn L, Steineck G (1999) Vaginal changes and sexuality in women with a history of cervical cancer. *The New England Journal of Medicine*, 340(18), 1383-1389.
- Blagbrough J (2010) Importance of sexual needs assessment in palliative care. *Nursing Standard*, 24(52), 35-39.
- Blattner W (1992) Existential Temporality in Being and Time. In: Dreyfus H, Hall H (Eds) *Heidegger: A Critical Reader*. Oxford: Blackwell Ltd, Ch.5, 99-129.
- BMJ Group and the Royal Pharmaceutical Society of Great Britain (2011) *British National Formulary: 62*. London: BMJ Publishing Group Ltd and RPS Publishing.
- Boehmer U and Case P (2004) Physicians Don't Ask, Sometimes Patients Tell: Disclosure of Sexual Orientation among Women with Breast Carcinoma. *Cancer*, 101(8), 1882-1889.
- Boulton M (2009) Research Ethics. In: Neale J (Ed) *Research Methods for Health and Social Care*. Palgrave Macmillan: Basingstoke, Ch.3, 31-45.
- Bowden G and Bliss J (2009) Does a hospital bed impact on sexuality expression in palliative care? *British Journal of Community Nursing*, 14(3), 122-126.
- Bowden G and Bliss J (2008) Does using a hospital bed have an impact on the meaning of home? *British Journal of Community Nursing*, 13(12), 556-562.
- Bowlby R (2007) Passionate about attachment. *Context* 90. April, 3-4.
- Bowlby J (1988) The role of attachment in personality development. In: *A Secure Base: Clinical Applications of Attachment Theory*. London: Routledge, Lecture 7, 119-136.
- Bowlby J (1985) Conceptual framework. In: *Attachment and Loss Volume 3: Loss, Sadness and Depression*. London: Penguin, Ch.3, 38-43.

- Bowlby J (1979) The making and breaking of affectional bonds. In: *The Making and Breaking of Affectional Bonds*. London: Routledge, Lecture 7, 126-160.
- Brecher E (1970) *The Sex Researchers*. London: Andre Deutsch Ltd.
- British Broadcasting Corporation (2012) *Government defends gay marriage law change plans*. BBC News. 12th June. Available at: <http://www.bbc.co.uk/news/uk-18412222> (Accessed on 20th June 2012)
- British Broadcasting Corporation (2010). *Vatican: Pope did not back Vatican contraception use*. BBC News. 21st December. Available at: <http://www.bbc.co.uk/news/world-europe-12053610> (Accessed on 20th September 2011)
- Brock P (2004) *A Passion for Life*. Sydney: ABC Books.
- Brown H, Croft-White C, Wilson C, Stein J (2000) *Taking the Initiative: Supporting the Rights of Disabled People*. Brighton: Pavilion Publishing.
- Burbie G and Polinsky M (1992) Intimacy and sexuality after cancer treatment: restoring a sense of wholeness. *Journal of Psychosocial Oncology*, 10(1), 19-33.
- Butler L, Banfield V, Terry S, Allen K (1998) Conceptualising sexual health in cancer care. *Western Journal of Nursing Research*, 20(6), 683-699.
- Caelli K (2000) The changing face of phenomenological research: traditional and American phenomenology in nursing. *Qualitative Health Research*, 10(3), 366-377.
- Cagle J and Bolte S (2009) Sexuality and life-threatening illness: implications for social work and palliative care. *Health and Social Work*, 34(3), 223-233.
- Cameron S, Springer C, Fox-Wasylyshyn S, El-Masri M (2012) A descriptive study of functions, symptoms, and perceived health state after radiotherapy for prostate cancer. *European Journal of Oncology Nursing*, 16(3), 310-314.
- Cancer Research UK (no date) *About sex and chemotherapy*. Available at: <http://cancerhelp.cancerresearchuk.org/about-cancer/treatment/chemotherapy/sex/about-sex-and-chemotherapy> (Accessed on 4th February 2012)
- Caplan P (Ed.) (1987) *The Cultural Construction of Sexuality*. London: Routledge.

Carolan M (2003) Reflexivity: a personal journey during data collection. *Nurse Researcher*, 10(3), 7-14.

Carpenter J (1998) Informing participants about the benefits of descriptive research. *Nursing Research*, 47(1), 63-64.

Carr D (2010) New perspectives on the Dual Process Model (DPM): what have we learned? What questions remain? *Journal of Death and Dying*, 61(4), 371-380.

Carr E and Mann E (2000) *Pain: Creative Approaches to Effective Management*. Basingstoke: Palgrave Macmillan.

Carter H, MacLeod R, Brander P, McPherson K (2004) Living with a terminal illness: patients' priorities. *Journal of Advanced Nursing*, 45(6), 611–620.

Caruso-Herman (1989) Concerns for the dying patient and family. *Seminars in Oncology Nursing*, 5(2), 120-123.

Casarett D and Karlawish J (2000) Are special ethical guidelines needed for palliative care research? *Journal of Pain and Symptom Management*, 20(2), 130-139.

Cerborne D (2006) *Understanding phenomenology*. Stocksfield: Acumen.

Chan S, Levy V, Chung T, Lee D (2002) A qualitative study of the experiences of a group of Hong Kong Chinese women diagnosed with post-natal depression. *Journal of Advanced Nursing*, 39(6), 571-579.

Chapple A (2006) Interviewing people with terminal illness: practical and ethical issues. *Nurse Researcher*, 14(1), 50-58.

Chartered Society of Physiotherapy (no date) *Facts and Statistics*. Available at: <http://www.csp.org.uk/press-policy/press-resources/facts-statistics> (Accessed on 8th April 2012)

Chaucer G (1385) Book V. In: *Troilus and Criseyde*. Available at: http://ebooks.gutenberg.us/DjVu_Collection/DJEDS/CHAUCER/TROILUS/Download.pdf (Accessed on 26th December 2011)

Chesney M (2000) Interaction and understanding: 'me' in the research. *Nurse Researcher*, 7(3), 58-69.

Church of England (2000) *The Marriage Service from Common Worship*. Available at: <http://www.churchofengland.org/prayer-worship/worship/texts/pastoral/marriage/marriage.aspx> (Accessed on 20th September 2011)

Churchill T (no date) *What are lightwriters?* Available at: <http://www.toby-churchill.com/content/lightwriters-0> (Accessed on 10th January 2012)

Clark R (1990) Forgiveness in the hospice setting. *Palliative Medicine* 4(4), 305-310.

Clarke J (1999) Hermeneutic analysis: a qualitative decision trail. *International Journal of Nursing Studies*, 36(5), 363-369.

Clarke LH (2003) Overcoming ambivalence: the challenges of exploring socially charged issues. *Qualitative Health Research*, 13(5), 718-735.

Clulow C (2001) Introduction. In: Clulow C (Ed.) *Adult Attachment and Couple Psychotherapy: the Secure Base in Practice and Research*. London: Routledge, 1-11.

Cohen M, Kahn D, Steeves R (2000) *Hermeneutic Phenomenological Research: A Practical Guide for Nurse Researchers*. London: Sage Publications Ltd.

Cohen M and Omery A (1994) Schools of phenomenology: implications for research. In: Morse J (Ed.) *Critical Issues in Qualitative Research*. London: Sage Publications Ltd, Ch.8, 136-156.

Cohen R and Mount B (1992) Quality of life in terminal illness: defining and measuring subjective well-being in the dying. *Journal of Palliative Care*, 8(3), 40-45.

Colbourne L and Sque M (2005) The culture of cancer and the therapeutic impact of qualitative research interviews. *Journal of Research in Nursing*, 10(5), 551-567.

Comfort A and Quilliam S (2008) *The Joy of Sex: The Timeless Guide to Lovemaking*. London: Octopus Publishing Group Ltd.

Conroy S (2003) A pathway for interpretive phenomenology. *International Journal of Qualitative Methods*, 2(3), 36-62.

Cook A and Bosley G (1995) The experience of participating in bereavement research: stressful or therapeutic? *Death Studies*, 19(2), 157-170.

- Coombes L, Allen D, Humphrey D and Neale J (2009) In-depth interviews. In: Neale J (Ed) *Research Methods for Health and Social Care*. Palgrave Macmillan: Basingstoke, Ch.14, 197-210.
- Cooper E and Guillebaud J (1999) *Sexuality and Disability: A Guide for Everyday Practice*. Abingdon: Radcliffe Medical Press.
- Corner J and Clark D (2002) Evaluating the work of clinical nurse specialists in palliative care. *Palliative Medicine*, 16(4), 275-277.
- Cort E, Monroe B, Oliviere D (2004) Couples in palliative care. *Sexual and Relationship Therapy*, 19(3), 337-354.
- Cosmopolitan (2011a) *Cosmopolitan*. London: Hearst Magazines UK, September.
- Cosmopolitan (2011b) *Cosmopolitan*. London: Hearst Magazines UK, October.
- Cosmopolitan (no date 1) *Love and Sex*. Available at: <http://www.cosmopolitan.co.uk/love-sex/?cmpid=lovesexnav> (Accessed on 13th September 2011)
- Cosmopolitan (no date 2) *Standing tiger / crouching dragon*. Available at: <http://www.cosmopolitan.co.uk/love-sex/karma-sutra/standing-tiger-crouching-dragon-78539> (Accessed on 13th September 2011)
- Cotterill P (1992) Interviewing women: issues of friendship, vulnerability and power. *Women's Studies International Forum*, 15(5/6), 593-606.
- Coveney L, Jackson M, Jeffreys S, Kay L, Mahony P (1984) Introduction. In: Coveney L, Jackson M, Jeffreys S, Kaye L, Mahony P (Eds.) *The Sexuality Papers: Male Sexuality and the Social Control of Women*. London: Hutchinson, 9-21.
- Creswell J (1998) *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. London: Sage Publications Ltd.
- Crew F (1952) Foreword. In: Ford C, Beach F (1952) *Patterns of Sexual Behaviour*. London: Eyre and Spottiswoode, p.vii.
- Crotty M (1996) *Phenomenology and Nursing Research*. Melbourne: Churchill Livingstone.

- Crouch S (1998) Sexuality, nursing and professional practice. In: Morrissey M (Ed.) *Sexuality and Healthcare: A Human Dilemma*. Dinton: Mark Allen Publishing, Ch.10, 189-208.
- Cutcliffe J (2002) Ethics committees, vulnerable groups and paternalism: the case for considering the benefits of participating in qualitative interviews. In: Dooher J, Byrt R (Eds) *Empowerment and Participation: Power, Influence and Control in Health Care*. London: Quay Books, Ch.13, 204-219.
- Cutcliffe J, Ramcharan P (2002) Leveling the playing field? Exploring the merits of the ethics-as-process approach for judging qualitative research proposals. *Qualitative Health Research*, 12(7), 1000-1010.
- Dallos R and Vetere A (2009) Love and sexuality. In: *Systemic Therapy and Attachment Narratives: Applications in a Range of Clinical Settings*. Hove: Routledge, Ch.5, 86-110.
- Dallos S and Dallos R (1997) *Couples, Sex and Power: the Politics of Desire*. Buckingham: Open University Press.
- Davies B, Reimer J, Brown P, Martens N (1995) Challenges of conducting research in palliative care. In: Davies et al *Fading Away: The Experience of Transition in Families with Terminal Illness*. New York: Baywood Publishing Company, Ch.12, 97-108.
- Davies E, Hall S, Clarke C, Bannon M, Hopkins A (1998) Do research interviews cause distress or interfere in management? *Journal of the Royal College of Physicians of London*, 32(5), 406-411.
- Davis L (2005) Visualizing the disabled body: the classical nude and disabled torso. In: Fraser M, Greco M (Eds.) *The Body: A Reader*. Abingdon: Routledge, Ch.23, 167-181.
- Davis S and Taylor B (2006) From PLISSIT to Ex-PLISSIT. In: Davis S (Ed.) *Rehabilitation: The Use of Theories and Models in Practice*. Oxford: Elsevier Ltd, Ch.6, 101-129.
- de Laine M (2000) *Fieldwork, Participation and Practice: Ethics and Dilemmas in Qualitative Research*. London: Sage Publications Ltd.

Demirkiran M, Sarica Y, Uguz S, Yerdelen D, Aslan K (2006) Multiple sclerosis patients with and without sexual dysfunction: are there any differences? *Multiple Sclerosis*, 12(2), 209-214.

Department of Health (2008) *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life. Executive Summary*. Available at: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086437.pdf (Accessed on 3rd June 2012)

de Raeve L (1994) Ethical issues in palliative care research. *Palliative Medicine*, 8(4), 298-305.

de Vocht H (2011) *Sexuality and Intimacy in Cancer and Palliative Care in the Netherlands: A Hermeneutic Study*. Unpublished PhD thesis. Birmingham: Birmingham City University.

de Vocht H, Hordern A, Notter J, van de Wiel H (2011) Stepped skills: a team approach towards communication about sexuality and intimacy in cancer and palliative care. *Australasian Medical Journal*, 4(11), 610-619.

de Witt L and Ploeg J (2006) Critical appraisal of rigour in interpretive phenomenological research. *Advances in Nursing Science*, 55(2), 215-229.

Diamond J (1998) *C: Because Cowards get Cancer too...* London: Vermilion.

Dickson-Swift V, James E, Liamputtong P (2008) *Undertaking Sensitive Research in the Health and Social Sciences: Managing Boundaries, Emotions and Risks*. Cambridge: Cambridge University Press.

Dickson-Swift V, James E, Kippen S, Liamputtong P (2007) Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research*, 7(3), 327-353.

Diekelmann J (2005) The retrieval of method: the method of retrieval. In: Ironside P (Ed.) *Beyond Method: Philosophical Conversations in Healthcare Research and Scholarship*. Madison, Wisconsin: The University of Wisconsin Press, Ch.1, 3-57.

Diekelmann N (1992) Learning-as-testing: A Heideggerian hermeneutical analysis of the lived experiences of students and teachers in nursing. *Advances in Nursing Science*, 14(3), 72-83.

Diekelmann N and Ironside P (2006) Hermeneutics. In: Fitzpatrick J (Ed) *Encyclopaedia of Nursing Research* (2nd edition). New York: Springer Publishing Company, 260-262.

Di Lillo D (2001) Interpersonal functioning among women reporting a history of childhood sexual abuse: empirical findings and methodological issues. *Clinical Psychology Review*, 21(4), 553-576.

Directgov (2011) *Understand grounds for divorce*. Available at:

http://www.direct.gov.uk/en/Governmentcitizensandrights/DivorceSeparationandRelationshipBreakdown/Endingamarriageorcivilpartnership/Gettingadivorce/DG_193734 (Accessed on 20th September 2011)

Doka K (2002a) Preface. In: Doka K (Ed.) *Disenfranchised Grief: New Directions, Challenges and Strategies for Practice*. Champaign, Illinois: Research Press, xiii-xv.

Doka K (2002b) Introduction. In: Doka K (Ed.) *Disenfranchised Grief: New Directions, Challenges and Strategies for Practice*. Champaign, Illinois: Research Press, Ch.1, 5-22.

Doka K (Ed.) (1989) *Disenfranchised Grief: Hidden Sorrow*. Lexington, MA: Lexington.

Dossey B, Keegan L, Guzzetta C (2008) *Holistic Nursing: A Handbook for Practice* (4th edition). London: Jones and Bartlett Publishers International.

Dowling M (2005) From Husserl to van Manen: A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44(1), 131-142.

Draucker CB (1999) The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing*, 30(2), 360-373.

Drew N (1989) The interviewer's experience as data in phenomenological research. *Western Journal of Nursing Research*, 11(4), 431-439.

Dreyfus H (1990) *Being-in-the-world*. Cambridge, MA: MIT Press.

Dyregrov K (2004) Bereaved parents' experience of research participation. *Social Science and Medicine*, 58(2), 391-400.

Ehrenreich B and English D (1979) *For Her Own Good. 150 years of the experts' advice to women*. London: Pluto Press.

- Elam G and Fenton K (2003) Researching sensitive issues and ethnicity: lessons from sexual health. *Ethnicity and Health*, 8(1), 15-27.
- Eliot TS (2001a) Burnt Norton. In: *Four Quartets*. London: Faber and Faber, 1-9. [First published in 1944]
- Eliot TS (2001b) Little Gidding. In: *Four Quartets*. London: Faber and Faber, 33-43. [First published in 1944]
- Ellis C (1995) *Final Negotiations: A Story of Love, Loss and Chronic Illness*. Philadelphia: Temple University Press.
- Ellis H (1913) *Studies in the Psychology of Sex, volumes 1-6*. Philadelphia: FA Davis.
- Ellis H, Symonds J (1897) *Sexual Inversion*. London: Wilson and Macmillan.
- Encyclopaedia Britannica (no date) *Epoche*. Available at: <http://www.britannica.com/EBchecked/topic/190459/epoche> (Accessed on 20th September 2011)
- Eriksen M, Hermansen T, Dean E, Riddick M, Swire R, Rihanna (2009) Rude boy. Sung by Rihanna, *Rate R*. Def Jam Recordings [Audio CD]
- Esmail S, Huang J, Lee I, Maruska T (2010) Couples' experiences when men are diagnosed with Multiple Sclerosis in the context of their sexual relationship. *Sexuality and Disability*, 28(1), 15-27.
- Esmail S, Munro B, Gibson N (2007) Couples' experience with multiple sclerosis in the context of their sexual relationship. *Sexuality and Disability*, 25(4), 163–177.
- Ewing G, Rogers M, Barclay S, McCabe J, Martin A, Todd C (2004) Recruiting patients into a primary care based study of palliative care: why is it so difficult? *Palliative Medicine*, 18(5), 452-459.
- Farkas C (1992) Neglected issues in the care of dying patients: nonverbal communication and sexuality. *Loss, Grief and Care*, 6(2-3), 125-129.
- Feldman P (1984) The homosexual preference. In: Howells K (Ed.) *The Psychology of Sexual Diversity*. Oxford: Basil Blackwell Ltd. Ch.1, 5-41.

- Fergus L and Keel M (2005) *Adult victim/survivors of childhood sexual assault*. Australian Centre for the Study of Sexual Assault Wrap, No.1, 1-6. Available at: <http://www.aifs.gov.au/acssa/pubs/wrap/w1.html> (Accessed on 26th December 2011)
- Fergusson D and Mullen P (1999) *Childhood Sexual Abuse: An Evidence Based Perspective*. London: Sage.
- Fine P (2003) Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life. *Journal of Pain and Symptom Management*, 25(4), s53-s62.
- Flandrin J-L (1985) Sex in married life in the early Middle Ages: the Church's teaching and behavioural reality. In: Ariès P and Béjin A (Eds.) *Western Sexuality: Practice and Precept in Past and Present Times*. Oxford: Basil Blackwell Ltd, Ch.10, 114-129.
- Flaskerud J and Winslow B (1998) Conceptualising vulnerable populations in health-related research. *Nursing Research*. 47(2), 69-78.
- Ford C and Beach F (1952) *Patterns of Sexual Behaviour*. London: Eyre and Spottiswoode.
- Foucault M (1998) *The Will to Knowledge. The History of Sexuality: Volume one* [Translated by Hurley R]. London: Penguin Books. [First published in 1976]
- Foucault M (1979) *Discipline and Punish*. New York: Vintage Books.
- Frank A (2002) *At the Will of the Body: Reflections on Illness*. New York: Mariner Books.
- Frank A (1997) Enacting illness stories: when, what and why? In: Lindemann Nelson H (Ed.) *Stories and their Limits: Narrative Approaches to Bioethics*. Chicago: University of Chicago Press, Ch.3, 31-49.
- Fraser M and Greco M (2005) *The Body: A Reader*. Abingdon: Routledge.
- French P (1983) *Social Skills for Nursing Practice*. London: Croom Helm.
- Freud S (1933) Lecture XXXIII 'Femininity'. In: *New Introductory Lectures on Psychoanalysis* [Translated by Strachey J] New York: WW Norton and Company, p.139-165.

- Freud S (1925) *Sexuality and the Psychology of Love* [Translated by Strachey J]. New York: Collier Books.
- Gabb J (2010) *Researching Intimacy in Families*. Basingstoke: Palgrave Macmillan.
- Gadamer H (1982) *Truth and Method*. New York: Crossroad.
- Gadamer H (1976) *Philosophical Hermeneutics* [Translated and edited by Linge D]. Berkeley, California: University of California Press.
- Gagnon J (2004) *An Interpretation of Desire: Essays in the Study of Sexuality*. Chicago: University of Chicago Press.
- Gagnon J and Simon W (2005) *Sexual Conduct: The Social Sources of Human Sexuality* (2nd edition). London: Aldine Transaction. [First published in 1973]
- Gaines R (1997) Detachment and continuity: the two tasks of mourning. *Contemporary Psychoanalysis*, 33(4), 549-571.
- Galdston (1954) So noble an effort corrupted. In: Geddes D (Ed.) *An Analysis of the Kinsey Report on Sexual Behaviour in the Human Male and Female*. New York: Mentor Books, 42-48.
- Gallagher D and Monroe B (2006) Psychosocial care. In: Oliver D, Borasio GD, Walsh D (Eds.) *Palliative Care in Amyotrophic Lateral Sclerosis: From Diagnosis to Bereavement*. Oxford: Oxford University Press. Ch.5, 143-168.
- Gamlin R (2005) Sexuality and palliative care. In: Lugton J, McIntyre R (Eds.) *Palliative Care: The Nursing Role* (2nd edition). London: Elsevier, Ch.7, 199-222.
- Gant R (1972) Publisher's note. In: Lawrence DH, *The First Lady Chatterley*. London: Heinemann, v-vii.
- Gelven M (1989) *A Commentary on Heidegger's Being and Time*. DeKalb, Illinois: Northern Illinois University Press.
- Gender A (1999) Clinical implications of sexual dysfunction in men on chronic haemodialysis. *Rehabilitation Nursing*, 24(1), 27.

- Gianotten W (2007) Sexuality in the palliative-terminal phase of cancer. *Sexologies*, 16(4), 299-303.
- Gibran K (1972) *The Prophet*. London: Heinemann.
- Giddens A (1992) *The Transformation of Intimacy*. Cambridge: Polity Press.
- Gilbert E, Ussher J, Hawkins Y (2009) Accounts of disruptions to sexuality following cancer: the perspective of informal carers who are partners of a person with cancer. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13(5), 523-541.
- Gilbert E, Ussher J, Perz J (2010) Renegotiating sexuality and intimacy in the context of cancer: the experience of carers. *Archives of Sexual Behaviour*, 39(4), 998-1009.
- Gilley J (1988) Intimacy and terminal care. *Journal of the Royal College of General Practitioners*, 38(308), 121-122.
- Glover J (1985) *Human Sexuality in Nursing Care*. London: Croom Helm.
- Goddard L (1988) Sexuality and spinal cord injury. *Journal of Neuroscience Nursing*, 20(4), 240-244.
- Goffman E (1990) *Stigma: Notes on the Management of Spoiled Identity*. Harmondsworth: Penguin.
- Gott (2005) *Sexuality, Sexual Health and Ageing*. Maidenhead: Open University Press.
- Gott M, Galena E, Hinchliff S, Elford H (2004) 'Opening a can of worms': GP and Practice Nurse barriers to talking about sexual health in primary care. *Family Practice*, 21(5), 528-536.
- Gott M and Hinchliff S (2003) How important is sex in later life? The views of older people. *Social Science and Medicine*, 56(8), 1617-1628.
- Gould P (2011) *When I die*. Available at: <http://www.mariecurie.org.uk/en-gb/who-we-are/philip-gould-when-i-die/?gclid=CJu1pPnnsbACFTMetAodskBaUw> (Accessed on 3rd June 2012)

- Greatrex-White S (2008) Thinking about the nature of research findings: a hermeneutic phenomenological perspective. *International Journal of Nursing Studies*, 45(12), 1842-1849.
- Gregory D, Russell C, Phillips L (1997) Beyond textual perfection: transcribers as vulnerable persons. *Qualitative Health Research*, 7(2), 294-300.
- Grigg E (2002) The issues of sexuality and intimacy in palliative care. In: Penson J, Fisher R (Eds) *Palliative Care for People with Cancer* (3rd edition). London: Arnold, Ch.9, 202-218.
- Groenewald T (2004) A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1), 42-55.
- Gullickson C (1993) My death nearing its future: a Heideggerian hermeneutical analysis of the lived experience of persons with chronic illness. *Journal of Advanced Nursing*, 18(9), 1386-1392.
- Guthrie C (1999) Nurses' perceptions of sexuality relating to patient care. *Journal of Clinical Nursing*, 8(3), 313-321.
- Gutting G (2005) *Foucault: A Very Short Introduction*. Oxford: Oxford University Press.
- Haboubi N and Lincoln N (2003) Views of health professionals on discussing sexual issues with patients. *Disability and Rehabilitation*, 25(6), 291-296.
- Hagman G (2001) Beyond decaethesis: toward a new psychoanalytic understanding and treatment of mourning. In: Neimeyer R (Ed.) *Reconstruction of the Experience of Loss*. Washington American Psychological Association, Ch.1, 13-31.
- Harman G (2007) *Heidegger Explained: From Phenomenon to Thing*. Chicago: Open Court.
- Hautamaki K, Miettinen M, Kellokumpu-Lehtinen P, Lehto J (2007) Opening communication with cancer patients about sexuality related issues. *Cancer Nursing*, 30(5), 399-404.

Haverkamp L, Appel V, Appel S (1995) Natural history of amyotrophic lateral sclerosis in a database population: validation of a scoring system and a model for survival prediction. *Brain*, 118(3), 707-719.

Hawkins Y, Ussher J, Gilbert E, Perz J, Sandoval M, Sundquist K (2009) Changes in sexuality and intimacy after the diagnosis and treatment of cancer. *Cancer Nursing*, 32(4), 271-280.

Healy M (2011) Heidegger's contribution to hermeneutic research. In: Thomson G, Dykes F, Downe S (Eds.) *Qualitative Research in Midwifery and Childbirth: Phenomenological Approaches*. London: Routledge, Ch.12, 215-232.

Heidegger M (2012) *Bremen and Freiburg Lectures: Insight into That Which is and Basic Principles of Thinking* [Translated by Mitchell A]. Indianapolis: Indian University Press. [First presented as lectures in 1949 and 1957]

Heidegger M (2010) *Being and Time* [Translated by Stambaugh J]. Albany: State University of New York Press. [First published in 1953]

Heidegger M (1977) The question concerning technology. In: *The Question Concerning Technology and other Essays* [Translated by Lovitt W]. New York: Harper Collins. [First published in 1954], 3-35.

Heidegger M (1962) *Being and Time* [Translated by Macquarrie J, Robinson E]. Oxford: Blackwell Publishing. [First published in 1927]

Heiman J, Long JS, Smith S, Fisher W, Sand M, Rosen R (2011) Sexual satisfaction and relationship happiness in midlife and older couples in five countries. *Archives of Sexual Behaviour*, 40(4), 741-753.

Hekman S (1983) From epistemology to ontology. Gadamer's Hermeneutics and Wittgensteinian Social Science, *Human Studies*, 6(3), 205-224.

Herbenick D, Reece M, Hollub A, Satinsky S, Dodge B (2008) Young female breast cancer survivors: their sexual function and interest in sexual enhancement products and services. *Cancer Nursing*, 31(6), 417-425.

Higgins A, Barker P, Begley C (2006) Sexuality: the challenge to espoused holistic care. *International Journal of Nursing Practice*, 12(6), 345-351.

- Hislop J (2007) A bed of roses or a bed of thorns? Negotiating the couple relationship through sleep. *Sociological Research Online*, 12(5)2. Available at: <http://www.socresonline.org.uk/12/5/2.html> (Accessed on 6th November 2011)
- Hite S (1976) *The Hite Report: A Nationwide Study of Female Sexuality*. New York: Dell Publishing Company.
- Hodge A (1995) Addressing issues of sexuality with spinal cord injured persons. *Orthopaedic Nursing*, 14(3), 21-24.
- Hogan N and de Santis L (1992) Adolescent sibling bereavement: an on-going attachment. *Qualitative Health Research*, 2(2), 159-177.
- Holloway I and Walker J (2000) *Getting a PhD in Health and Social Care*. Oxford: Blackwell Science Ltd.
- Holloway I and Wheeler S (2002) *Qualitative Research in Nursing* (2nd edition). Oxford: Blackwell Science Ltd.
- Hordern A (2008) Intimacy and sexuality after cancer: a critical review of the literature. *Cancer Nursing*, 31(2), 9-17.
- Hordern A (2000) Intimacy and sexuality for the woman with breast cancer. *Cancer Nursing*, 23(3), 230-236.
- Hordern A and Currow D (2003) A patient-centred approach to sexuality in the face of life-limiting illness. *Medical Journal of Australia*, 179(6), S8-S11.
- Hordern A, Grainger M, Hegarty S, Jefford M, White V, Sutherland G (2009) Discussing sexuality in the clinical setting: the impact of a brief training programme for oncology health professionals to enhance communication about sexuality. *Asia-Pacific Journal of Clinical Oncology*, 5(4), 270-277.
- Hordern A and Street A (2007a) Constructions of sexuality and intimacy after cancer: patient and health professionals perspectives. *Social Science and Medicine*, 64(8), 1704-1718.

Hordern A and Street A (2007b) Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. *Medical Journal of Australia*, 186(5), 224-227.

Hughes M (2000) Sexuality and the cancer survivor: a silent coexistence. *Cancer Nursing*, 23(6), 477-482.

Hughes M (1997) Sexuality issues of the cancer survivor. *Coping*, 11(2), 51-52.

Husserl E (1970) *The Crisis of European Sciences and Transcendental Phenomenology* [Translated by Carr D]. Evanston: Northwestern University Press. [First published in 1936]

Husserl E (1962) *Ideas: General Introduction to Pure Phenomenology* [Translated by Gibson WR]. New York: Collier. [First published in 1913]

Hutchinson S, Wilson M, Wilson HS (1994) Benefits of participating in research interviews. *Journal of Nursing Scholarship*, 26(2), 161-164.

Ironside P (2005) Introduction. In: Ironside P (Ed.) *Beyond Method: Philosophical Conversations in Healthcare Research and Scholarship*. Madison, Wisconsin: The University of Wisconsin Press, ix-xix.

Ironside P, Scheckel M, Wessels C, Bailey M, Powers S, Seeley D (2003) Experiencing chronic illness: cocreating new understandings. *Qualitative Health Research*, 13(2), 171-183.

Irwin R (2000) Treatments for patients with sexual problems. *Professional Nurse*, 15(6), 360-364.

Jackson M (1984a) Sexology and the universalisation of male sexuality (from Ellis to Kinsey, and Masters and Johnson). In: Coveney L, Jackson M, Jeffreys S, Kaye L, Mahony P (Eds.) *The Sexuality Papers: Male Sexuality and the Social Control of Women*. London: Hutchinson, Ch.3, 69-84.

Jackson M (1984b) Sexology and the social construction of male sexuality (Havelock Ellis) In: Coveney L, Jackson M, Jeffreys S, Kaye L, Mahony P (Eds.) *The Sexuality Papers: Male Sexuality and the Social Control of Women*. London: Hutchinson, Ch.2, 45-68.

- Jackson S (1978) *On the Social Construction of Female Sexuality*. London: Women's Research and Resources Centre Publications.
- Jacobs H, Vieregge A, Vieregge P (2000) Sexuality in young patients with Parkinson's disease: a population based comparison with healthy controls. *Journal of Neurology, Neurosurgery and Psychiatry*, 69(4), 550-552.
- Jamieson L (2005) Boundaries of intimacy. In: McKie L, Cunningham-Burley S (Eds.) *Families in Society: Boundaries and Relationships*. Bristol: Policy Press, Ch.4, 189-206.
- Janes E and Shirley L (2008) Challenging behaviour: acknowledging the man, not the behaviour. *Journal of Dementia Care*, 16(1), 20-24.
- Jasper M (1994) Issues in phenomenology for researchers of nursing. *Journal of Advanced Nursing*, 19(2), 309-314.
- Jeffcoate T (1967) *Principles of Gynecology*. London: Butterworth. Cited in: Scully D, Bart P (1973) A funny thing happened on the way to the orifice: women in gynaecology textbooks. *American Journal of Sociology*, 78(4), 1045-1050.
- Jeffreys S (1984) 'Free from all uninvited touch of man': women's campaigns around sexuality, 1880-1914. In: Coveney L, Jackson M, Jeffreys S, Kaye L, Mahony P (Eds.) *The Sexuality Papers: Male Sexuality and the Social Control of Women*. London: Hutchinson, Ch.1, 22-44.
- Johnson M (2000) Heidegger and meaning: implications for phenomenological research. *Nursing Philosophy*, 1(2), 134-146.
- Johnson A, Mercer C, Erens B, Copas A, McManus S, Wellings K, Fenton K, Korovessis C, Macdowall W, Nanchahal K, Purdon S, Field J (2001) Sexual behaviour in Britain: partnerships, practices and HIV risk behaviours. *Lancet*, 358(9296), 1835-1842.
- Johnson W and Delamater J (1976) Response effects in sex surveys. *Public Opinion Quarterly*, 40(2), 165-181.
- Jun E-Y, Kim S, Chang S-B, Oh K, Kang HS, Kang SS (2011) The effect of a sexual life reframing program on marital intimacy, body image and sexual function among breast cancer survivors. *Cancer Nursing*, 34(2), 142-149.

- Kahn D (2000) How to conduct research. In: Cohen Z, Kahn D, Steeves R (Eds.) *Hermeneutic Phenomenological Research: A Practical Guide for Nurse Researchers*. London: Sage Publications Ltd, Ch.6, 57-70.
- Karlen A (2002) Positive sexual effects of chronic illness: case studies of women with lupus (SLE). *Sexuality and Disability*, 20(3), 191-208.
- Kaub-Witteimer D, von Steinbüchel N, Wasner M, Laier-Groeneveld G, Borasio G (2003) Quality of life and psychosocial issues in ventilated patients with amyotrophic lateral sclerosis and their caregivers. *Journal of Pain and Symptom Management*, 26(4), 890-896.
- Kaufman M, Silverberg C, Odette F (2003) *The Ultimate Guide to Sex and Disability*. San Francisco, CA: Cleis Press Inc.
- Kavanagh K (2007) Meaning in suffering: a patchwork remembering. In: Johnston N and Scholler-Jaquish A (Eds.) *Meaning in Suffering: Caring Practices in the Health Professions*. Madison, Wisconsin: University of Wisconsin Press, Ch.1, 7-59.
- Keighley A (2002) Sexuality and people with a learning disability. In: Heath H, White I (Eds.) *The Challenge of Sexuality in Health Care*. Oxford: Blackwell Science Ltd, Ch.7, 107-121.
- Keller E and Bzdek V (1986) Effects of therapeutic touch on tension headache pain. *Nursing Research*, 35(2), 101-106.
- Kinsey A, Pomeroy W, Martin C (1948) *Sexual Behavior in the Human Male*. Bloomington: Indiana University Press.
- Kinsey A, Pomeroy W, Martin C, Gebhard P (1953) *Sexual Behavior in the Human Female*. Philadelphia: WB Saunders Company.
- Klass D, Silverman P, Nickman S (Eds.) (1996) *Continuing Bonds: New Understandings of Grief*. London: Taylor and Francis Ltd.
- Knaack P (1984) Phenomenological research. *Western Journal of Nursing Research*, 6(1), 107-123.
- Koch T (1996) Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation. *Journal of Advanced Nursing*, 24(1), 174-184.

- Koch T (1995) Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21(5), 827-836.
- Koch T (1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, 19(5), 976-986.
- Kotronoulas G, Papadopoulou C, Patiraki E (2009) Nurses' knowledge, attitudes, and practice regarding provision of sexual health care in patients with cancer: critical review of the evidence. *Supportive Care in Cancer*, 17(5), 479-501.
- Kreiter M, Sullivan M, Siorsteen A (1994) Sexual adjustment after spinal cord injury focusing on partner experiences. *Paraplegia*, 32(4), 225-235.
- Krell D (1993) *Martin Heidegger: Basic Writings*. Abingdon: Routledge, Kegan and Paul.
- Kutner J, Kassner C, Nowels D (2001) Symptom burden at the end of life: hospice providers' perceptions. *Journal of Pain and Symptom Management*, 21(6), 473-480.
- Kvale S (1996) *Interviews: An Introduction to Qualitative Research Interviewing*. London: Sage Publications Ltd.
- Larossa R, Bennett L, Gelles R (1981) Ethical dilemmas in qualitative family research. *Journal of Marriage and the Family*, 43(2), 303-313. Chicago: University of Chicago Press.
- Laumann E, Gagnon J, Michael R, Michaels S (1994) *The Social Organization of Sexuality: Sexual Practices in the United States*. Chicago: University of Chicago Press.
- Laury G (1987) Sexuality of the dying patient. *Medical Aspects of Human Sexuality*, June, 102-109.
- Laverty S (2003) Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal of Qualitative Methods*, 2(3), 1-29.
- Lavin M and Hyde A (2006) Sexuality as an aspect of nursing care for women receiving chemotherapy for breast cancer in an Irish context. *European Journal of Oncology Nursing*, 10(1), 10-18.
- Lawrence DH (1972) *The First Lady Chatterley*. London: Heinemann. [First published in 1928 as 'The Author's Unabridged Popular Edition']

- Lawrence DH (1960) *Lady Chatterley's Lover*. London: Penguin Books.
- Lawton J (2001) Gaining and maintaining consent: ethical concerns raised in a study of dying patients. *Qualitative Health Research*, 11(5), 693-705.
- Lee R (1993) *Doing Research on Sensitive Topics*. London: Sage Publications Ltd.
- Leiber L, Plumb M, Gerstenzang M, Holland J (1976) The communication of affection between cancer patients and their spouses. *Psychosomatic Medicine*, 38(6), 379-389.
- Lemieux L, Kaiser S, Pereira J, Meadows L (2004) Sexuality in palliative care: patient perspectives. *Palliative Medicine*, 18(7), 630-637.
- Leonard L and Follette V (2002) Sexual functioning in women reporting a history of childhood sexual abuse: review of the empirical literature and clinical implications. *Annual Review of Sex Research*, 13, 346-388.
- Leonard L, Iverson K, Follette V (2008) Sexual functioning and sexual satisfaction among women who report a history of childhood and/or adolescent sexual abuse. *Journal of Sex and Marital Therapy*, 34(5), 375-384.
- Leviton D (1978) The intimacy / sexual needs of the terminally ill and the widowed. *Death Education*, 2(3), 261-280.
- Liamputtong P (2007) *Researching the Vulnerable*. London: Sage Publications Ltd.
- Lion E (1989) *Sexuality of the dying: what dying participants, their spouses and caregivers teach us about the sexuality of the dying*. Unpublished PhD thesis. Indianapolis: Indiana University.
- Lion E (1982) Human sexuality: a concept basic to nursing. In: Lion E (Ed.) *Human Sexuality in Nursing Process*. New York: John Wiley and Sons, Ch.1, 5-17.
- Little M, Jordens C, Paul K, Sayers E (2001) *Surviving Survival: Life after Cancer*. Sydney: Choice Books.
- Lloyd V, Gatherer A, Kalsy S (2006) Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research*, 16(10), 1386-1404.

- Loe M (2001) Fixing broken masculinity: Viagra as a technology for the production of gender and sexuality. *Sexuality and Culture*, 5(3), 97-125.
- Lowes L and Gill P (2006) Participants' experiences of being interviewed about an emotive topic. *Journal of Advanced Nursing*, 55(5), 587-595.
- Lowes L and Prowse M (2001) Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies*, 38(4), 471-480.
- Mackey M (2007) Evaluation of qualitative research. In: Munhall P (Ed.) *Nursing Research: A Qualitative Perspective* (4th edition). London: Jones and Bartlett Publishers International, Ch.25, 555-568.
- Mackey S (2005) Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing Studies*, 42(2), 179-186.
- Maddineni S, Lau M, Sangar V (2009) Identifying the needs of penile cancer sufferers: a systematic review of the quality of life, psychosexual and psychosocial literature in penile cancer. *BMC Urology*, 9(8). Open access available at: <http://www.biomedcentral.com/1471-2490/9/8> (Accessed on 8th January 2012)
- Madjar I and Walton J (1999) Epilogue. In: Madjar I, Walton J (Eds.) *Nursing and the Experience of Illness: Phenomenology in Practice*. London: Routledge, 189-191.
- Maggs-Rapport F (2001) 'Best practice research': in pursuit of methodological rigour. *Journal of Advanced Nursing*, 35(3), 373-383.
- Magnan M, Reynolds K, Galvin E (2005) Barriers to addressing patient sexuality in nursing practice. *Medsurg Nursing*, 14(5), 282-289.
- Malacrida C (2007) Reflexive journaling on emotional research topics: ethical issues for team members. *Qualitative Health Research*, 17(10), 1329-1339.
- Malinowski B (1927) *Sex and Repression in Savage Society*. London: Routledge and Kegan Paul.

- Marsden R and Botell R (2010) Discussing sexuality with patients in a motor neurone disease clinic. *Nursing Standard*, 25(15-17) 39-45.
- Marsden R and Taylor B (2012a) *Leaflet 20A: Sex and Relationships: for People Living with MND*. Northampton: Motor Neurone Disease Association.
- Marsden R and Taylor B (2012b) *Leaflet 20B: Sex and Relationships: for Partners of People Living with MND*. Northampton: Motor Neurone Disease Association.
- Martyn E (2003) *Before you say 'I do'. How to be Happily Married for Ever*. London: Vermilion.
- Mason J (2002) *Qualitative Researching* (2nd edition). London: Sage Publications Ltd.
- Masters W and Johnson V (1974) *The Pleasure Bond: A New Look at Sexuality and Commitment*. Toronto: Bantam Books.
- Masters W and Johnson V (1970) *Human Sexual Inadequacy*. London: JA Churchill Ltd.
- Masters W and Johnson V (1966) *Human Sexual Response*. Boston: Little, Brown and Company.
- Matzo M and Hijazi K (2009) If you don't ask me ... don't expect me to tell. *Journal of Hospice and Palliative Nursing*, 11(5), 271-281.
- Mauthner N and Doucet A (2003) Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413-431.
- McCleod J (2007) *Counselling Skill*. Maidenhead: Open University Press.
- McConnell-Henry C, Chapman Y, Francis K (2011) Member checking and Heideggerian phenomenology: a redundant component. *Nurse Researcher*, 18(2), 28-37.
- McCosker H, Barnard A, Gerber R (2001) Undertaking sensitive research: issues and strategies for meeting the safety needs of all participants. *Forum: Qualitative Social Research*, 2(1), Art.22.
- Medlar T and Medlar J (1990) Nursing management of sexuality issues. *Journal of Head Trauma Rehabilitation*, 5(2), 46-61.
- Men's Health (2011a) *Men's Health*. London: NatMag Rodale Ltd, September.

- Men's Health (2011b) *Men's Health*. London: NatMag Rodale Ltd, October.
- Men's Health (2011c) How to give her an über-orgasm. *Men's Health*, October, p.126.
- Mick J (2007) Sexuality assessment: ten strategies for improvement. *Clinical Journal of Oncology Nursing*, 11(5), 671-675.
- Mick J, Hughes M, Cohen MZ (2004) Using the BETTER model to assess sexuality. *Clinical Journal of Oncology Nursing*, 8(1), 84-86.
- Miller J (1997) Researching violence against street prostitutes: issues of epistemology, methodology and ethics. In: Schwartz M (Ed.) *Researching Sexual Violence Against Women: Methodological and Personal Perspectives*. London: Sage Publications Ltd, Ch.11, 144-156.
- Miller E and Omarzu J (1998) New directions in loss research. In: Harvey J (Ed.) *Perspectives on Loss: A Sourcebook*. London: Brunner/Mazel. Ch.1, 3-20.
- Mishler E (1986) *Research Interviewing: Context and Narrative*. London: Harvard University Press.
- Mitchell A (2011) *The Thing and Technology: An Introduction to Late Heidegger*. Unpublished syllabus for the Institute for Hermeneutic Phenomenology, Indianapolis. 20th-23rd June.
- Monroe B (1999) *Time for intimacy: intimacy, sexuality and end of life*. Oral presentation at European Association of Palliative Care conference, Geneva. 22nd-24th September.
- Monroe B and Sheldon F (2004) Psychosocial dimensions of care. In: Sykes N, Edmonds P, Wiles J (Eds.) *Management of Advanced Disease* (4th edition). London: Arnold, Ch.16, 405-437.
- Morgan K (2010) Fatigue and lethargy in palliative care. *InnovAiT*, 3(4), 225-231.
- Morris S (2001) Joint and individual interviewing in the context of cancer. *Qualitative Health Research*, 11(4), 553-567.
- Morse J (2002) Interviewing the ill. In: Gubrium J, Holstein J (Eds.) *Handbook of Interview Research: Context and Method*. London: Sage Publications Ltd, Ch.16, 317-328.

- Morse J (2001) Are there risks in qualitative research? *Qualitative Health Research*, 11(1), 3-4.
- Morse J (2000) Researching illness and injury: methodological considerations. *Qualitative Health Research*, 10(4), 538-546.
- Morse J, Barrett M, Mayan M, Olson K, Spiers J (2002) Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 1-19.
- Morse J and Mitcham C (1997) Compathy: the contagion of physical distress. *Journal of Advanced Nursing*, 26(4), 649-657.
- Moustakas C (1994) *Phenomenological Research Methods*. London: Sage Publications Ltd.
- Mulhall S (2005) *Heidegger and Being and Time* (2nd edition). London: Routledge.
- Munhall P (2007) *Nursing Research: A Qualitative Perspective* (4th edition). London: Jones and Bartlett Publishers International.
- Munhall P (1989) Philosophical ponderings on qualitative research methods in nursing. *Nursing Science Quarterly*, 2(1), 20-28.
- Munhall P (1988) Ethical considerations in qualitative research. *Western Journal of Nursing Research*, 10(2), 150-162.
- Murray B (2003) Qualitative research interviews: therapeutic benefits for participants. *Journal of Psychiatric and Mental Health Nursing*, 10(2), 231-238.
- National Consensus Project for Palliative Care (2009) *Clinical Practice Guidelines for Quality Palliative Care* (2nd edition). Pittsburgh: National Consensus Project for Palliative Care.
- National Council of Hospice and Specialist Palliative Care Services (1993) *Specialist Palliative Care: A Statement of Definitions*. Northampton: Land and Unwin Ltd.
- National Gold Standards Framework Centre (2012) *Information for Patients, Families and Carers. How the GSF helps?* Available at:

[http://www.goldstandardsframework.org.uk/Information+ or Patients Families and Carers/HowtheGSFhelps](http://www.goldstandardsframework.org.uk/Information+or+Patients+Families+and+Carers/HowtheGSFhelps) (Accessed on 19th May 2012)

National Survey of Sexual Health and Behavior (NSSHB) (2010) Findings from the National Survey of Sexual Health and Behavior. *Journal of Sexual Medicine*, 7(5), 243-373.

Neimeyer R (2001) Introduction. In: Neimeyer R (Ed.) *Reconstruction of the Experience of Loss*. Washington: American Psychological Association, 1-9.

Newson P (2007) Sexuality: let's talk about it. *Nursing and Residential Care*, 9(8), 350-354.

Noble A and Jones C (2005) Palliative care. Benefits of narrative therapy: holistic interventions at the end of life. *British Journal of Nursing*, 14(6), 330-333.

Nolan M and Nolan J (1998) Rehabilitation in multiple sclerosis: the potential nursing contribution. *British Journal of Therapy and Rehabilitation*, 5(7), 370-375.

Northcott R and Chard G (2000) Sexual aspects of rehabilitation: the client's perspective. *British Journal of Occupational Therapy*, 63(9), 412-418.

Nursing and Midwifery Council (2010) *Standards for Pre-registration Nursing Education: Explanation of Terms*. London: Nursing and Midwifery Council. Available at: <http://standards.nmc-uk.org/PublishedDocuments/Section%204%20-%20Explanation%20of%20Terms%2020100916.pdf> (Accessed on 26th March 2012)

Nursing and Midwifery Council (2009) *Guidance for the Care of Older People*. London: Nursing and Midwifery Council.

Nyatanga B (2012) From bowel habits to sexuality: the taboos of caring in palliative care. *British Journal of Community Nursing*, 17(5), 210-211.

Odey K (2009) Legitimizing patient sexuality and sexual health to provide holistic care. *Gastrointestinal Nursing*, 7(8), 43-47.

Oiler C (1982) The phenomenological approach in nursing research. *Nursing Research*, 31(3), 178-181.

Oliver M (2004) Bone. In: *Why I Wake Early*. Boston: Beacon Press, 4-6.

Oliviere D, Hargreaves R, Monroe B (1998) Gender and sexuality. In: *Good Practices in Palliative Care: A Psychosocial Perspective*. Aldershot: Ashgate Publishing Ltd. Ch.5, 95-119.

Onions C (Ed.) (1983) *The Shorter Oxford English Dictionary* (3rd edition). London: Guild Publishing.

Orbach S (2007) Separated attachments and sexual aliveness: how changing attachment patterns can enhance intimacy. *New Directions in Psychotherapy and Relational Psychoanalysis*, 1(1), 8-17.

Ostrander N (2009) Sexual pursuits of pleasure among men and women with spinal cord injuries. *Sexuality and Disability*, 27(1), 11-19.

Ostrander N (2008a) When identities collide: masculinity, disability, and race. *Disability and Society*, 23(6), 585–597.

Ostrander R (2008b): Meditations on a bullet: violently-injured men discuss disability, masculinity, and blame. *Child and Adolescent Social Work Journal*, 25(1), 71–84.

Padula C (1996) Older couples' decision-making on health issues. *Western Journal of Nursing Research*, 18(6), 675-687.

Paley J (1997) Husserl, phenomenology and nursing. *Journal of Advanced Nursing*, 26(1), 193-197.

Parsons-Suhl K, Johnson M, McCann J, Solberg S (2008) Losing one's memory in early Alzheimer's disease. *Qualitative Health Research*, 18(1), 31-42.

Patton M (2002) *Qualitative Research and Evaluation Methods* (3rd edition). London: Sage Publications.

Peace G (1996) More than meets the eye. *Nursing Times*, 92(33), 44-45.

Peate I (2010) The sexual being. In: Peate I (Ed.) *Nursing Care and the Activities of Living*. Chichester: Wiley-Blackwell. Ch.13, 236-254.

Plager K (1994) Hermeneutic phenomenology: a methodology for family health and promotion study in nursing. In: Benner P (Ed.) *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness*. London: Sage Publications, Ch.4, 65-84.

- Pleschberger S, Seymour J, Payne S, Deschepper R, Onwuteaka-Philipsen B, Rurup M (2011) Interviews on end-of-life care with older people: reflections on six European studies. *Qualitative Health Research*, 21(11), 1588-1600.
- Plummer K (2005) Foreword. Permanence and change: Sexual conduct ~ thirty years on. In: Gagnon J, Simon W (2005) *Sexual Conduct: The Social Sources of Human Sexuality* (2nd edition). London: Aldine Transaction, ix-xxi. [First published in 1973]
- Polit D and Beck C (2004) *Nursing Research: Principles and Methods* (7th edition). London: Lippincott Williams and Wilkins.
- Polit D and Hungler B (1991) *Nursing Research: Principles and Methods* (3rd edition). Philadelphia: Lippincott.
- Polkinghorne D (1989) Phenomenological research methods. In: Valle R and Halling S (Eds.) *Existential Phenomenological Perspectives in Psychology: Exploring the Breadth of Human Experience*. New York: Plenum, Ch.3, 41-60.
- Polt R (2010) Being and time. In: Davis B (Ed.) *Martin Heidegger: Key Concepts*. Durham: Acumen, Ch.5, 69-81.
- Pontin D (2000) Interview. In: Cormack D (Ed.) *The Research Process in Nursing* (4th edition). Oxford: Blackwell Science Ltd, Ch.24, 289-299.
- Portenoy R, Thaler H, Kornblith A, Lepore J; Friedlander-Klar H; Kiyasu E; Sobel K; Coyle N; Kemeny N; Norton L; Scher H (1994) The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer*, 30(9), 1326-1336.
- Potts A, Gavey N, Grace V, Vares T (2003) The downside of Viagra: women's experiences and concerns. *Sociology of Health and Illness*, 25(7), 697-719.
- Potts A, Grace V, Gavey N, Vares T (2004) "Viagra stories": challenging 'erectile dysfunction'. *Social Science and Medicine*, 59(3), 489-499.
- Powers B and Knapp T (1995) *A Dictionary of Nursing Theory and Research* (2nd Edition). London: Sage Publications Ltd.

- Pratt R (2000) Introduction. Sexual health and disease: an international perspective. In: Wilson S, McAndrew S (Eds.) *Sexual Health: Foundations for Practice*. Edinburgh: Baillière Tindall, 1-6.
- Pulerwitz J, Amaro H, De Jong W, Gortmaker S, Rudd R (2002) Relationship power, condom use and HIV risk among women in the USA. *Aids Care*, 14(6), 789–800.
- Quilliam S (1995) *The Relate Guide to Staying Together. From Crisis to Deeper Commitment*. London: Vermilion.
- Racher F (2003) Using conjoint interviews to research the lived experience of elderly rural couples. *Nurse Researcher*, 10(3), 60-72.
- Racher F and Robinson S (2002) Are phenomenology and postpositivism strange bedfellows? *Western Journal of Nursing Research*, 25(5), 464-481.
- Radbruch L, Strasser F, Elsner F, Gonçalves J, Løge J, Kaasa S, Navck F, Stone P (2008) Fatigue in palliative care patients: an EAPC approach. *Palliative Medicine*, 22(1), 13-32.
- Radley A and Billig M (1996) Accounts of health and illness: dilemmas and representations. *Sociology of Health and Illness*, 18(2), 220-240.
- Ratzinger J (2003) *Considerations Regarding Proposals to give Legal Recognition to Unions between Homosexual Persons*. 28th March. Available at: http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20030731_homosexual-unions_en.html (Accessed on 20th September 2011)
- Raudonis B (1992) Ethical considerations in qualitative research with hospice patients. *Qualitative Health Research*, 2(2), 238-249.
- Ray M (1994) The richness of phenomenology: philosophic, theoretic and methodologic concerns. In: Morse J (Ed.) *Critical Issues in Qualitative Research Methods*. London: Sage Publications Ltd, Ch.7, 117-133.
- Redelman M (2008) Is there a place for sexuality in the holistic care of patients in the palliative care phase of life? *American Journal of Hospice and Palliative Care*, 25(5), 366-371.

Rellini A (2008) Review of the empirical evidence for a theoretical model to understand the sexual problems of women with a history of CSA. *Journal of Sexual Medicine*, 5(1), 31-46.

Rice A (2000) Sexuality in cancer and palliative care 2: exploring the issues. *International Journal of Palliative Nursing*, 6(9), 448-453.

Richards M and Ramirez A (1997) Quality of life: the main outcome measure of palliative care. *Palliative Medicine*, 11(2), 89-92.

Ricoeur P (1981) *Hermeneutics and the Human Sciences*. Cambridge: Cambridge University Press.

Riley A and Riley E (2000) Behavioural and clinical findings in couples where the man presents with erectile disorder: a retrospective study. *International Journal of Clinical Practice*, 54(4), 220-224.

Roe B and May C (1999) Incontinence and sexuality: findings from a qualitative perspective. *Journal of Advanced Nursing*, 30(3), 573-579.

Rogers M and Kristjanson L (2002) The impact on sexual functioning of chemo-therapy induced menopause in women with breast cancer. *Cancer Nursing*, 25(1), 57-65.

Romanoff B (2001) Research as therapy: the power of narrative to effect change. In: Neimeyer R (Ed.) *Reconstruction of the Experience of Loss*. Washington: American Psychological Association, Ch.13, 245-257.

Roper N, Logan W, Tierney A (1980) *The Elements of Nursing*. Edinburgh: Churchill Livingstone.

Rose K (1994a) Unstructured and semi-structured interviewing. *Nurse Researcher*, 1(3), 23-32.

Rose L (1994b) Homophobia among doctors. *British Medical Journal*. 308(6928), 586-587.

Rothenberg M and Dupras A (2010) Sexuality of individuals in the end-of-life stage. *Sexologies*, 19(3), 147-152.

Royal College of Nursing (2011) *Older People in Care Homes: Sexuality and Intimate Relationships*. London: Royal College of Nursing.

Royal College of Nursing (2000) *Sexuality and Sexual Health in Nursing Practice*. London: Royal College of Nursing.

Rubin L (1990) *Intimate Strangers: Men and Women Together*. London: Harper Collins.

Rust J and Golombok S (2007) *The Handbook of the Golombok Rust Inventory of Sexual Satisfaction (GRISS)*. London: Pearson Assessment.

Ryan F, Coughlan M, Cronin P (2009) Interviewing in qualitative research: the one-to-one interview. *International Journal of Therapy and Rehabilitation*, 16(6), 309-314.

St Luke's Hospice (2010) *Ethos and History*. Available at: <http://www.stlukes-hospice.org.uk/ethos.aspx> (Accessed on 19th May 2012)

Sainty M, Lambkin C, Maile L (2009) 'I feel so much safer': unravelling community equipment outcomes. *British Journal of Occupational Therapy*, 72(11), 499-506.

Sakellariou D (2006) If not the disability, then what? Barriers to reclaiming sexuality following spinal cord injury. *Sexuality and Disability*, 24(2), 101-111.

Sakellariou D and Sawada Y (2006) Sexuality after spinal cord injury: the Greek male's perspective. *American Journal of Occupational Therapy*, 60(3), 311-319.

Sandelowski M (1993) *With Child in Mind: Studies of the Personal Encounter with Infertility*. Pennsylvania: University of Pennsylvania Press.

Saunamäki N, Andersson M, Engström M (2010) Discussing sexuality with patients: nurses' attitudes and beliefs. *Journal of Advanced Nursing*, 66(6), 1308-1316.

Saunders C (1976) Care of the dying – 1: The problem of euthanasia. *Nursing Times*, 72(26), 1003-1005.

Saunders C and Baines M (1983) *Living with Dying: The Management of Terminal Disease*. Oxford: Oxford University Press.

Scandlyn J (2000) When AIDS became a chronic disease. *Western Journal of Medicine*, 172(2), 130-133.

Schilder P (1950) *The Image and Appearance of the Human Body*. New York: International Universities Press.

- Schmidt L (2006) *Understanding Hermeneutics*. Stocksfield: Acumen Publishing.
- Schon M (1968) The meaning of death and sex to cancer patients. *The Journal of Sex Research*, 4(4), 288-302.
- Schover L (1991) The impact of breast cancer on sexuality, body image and intimate relationships. *CA: A Cancer Journal for Clinicians*, 41(2), 112-120.
- Schover L, Yetman R, Tuason L, Meisler E, Esselsfyn C, Hermann R, Grundfest-Broniatowski S, Dowden R (1995) Partial mastectomy and breast reconstruction: a comparison of their effects on psychosocial adjustment, body image and sexuality. *Cancer*, 75(1), 54-64.
- Sciascia P (1995) From old to old to new. In: Wilson Schaef A (Ed.) *Native Wisdom for White Minds: Daily Reflections Inspired by the Native Peoples of the World*. Toronto: Random House of Canada Ltd, 15.
- Scott C (2010) Care and authenticity. In: Davis B (Ed.) *Martin Heidegger: Key concepts*. Durham: Acumen, Ch.4, 57-68.
- Scully D and Bart P (1973) A funny thing happened on the way to the orifice: women in gynaecology textbooks. *American Journal of Sociology*, 78(4), 1045-1050.
- Searle E (2002) Sexuality and people who are dying. In: Heath H, White I (Eds.) *The Challenge of Sexuality in Health Care*. Oxford: Blackwell Science, Ch.10, 153-166.
- Seidl A, Bullough B, Haughey B, Scherer Y, Rhodes M, Brown G (1991) Understanding the effects of a myocardial infarction on sexual functioning: a basis for sexual counselling. *Rehabilitation Nursing*, 16(5), 255-264.
- Sembera R (2007) *Rephrasing Heidegger: A Companion to Being and Time*. Ottawa, Ontario: University of Ottawa Press.
- Seymour J, Payne S, Reid D, Sargeant A, Skillbeck J, Smith P (2005) Ethical and methodological issues in palliative care studies: the experiences of a research group. *Journal of Research in Nursing*, 10(2), 169-188.
- Shakespeare T, Gillespie-Sells K, Davies D (1996) *The Sexual Politics of Disability*. London: Cassell.

- Sheldon F and Sargeant A (2007) Ethical and practical issues in qualitative research. In: Addington-Hall J, Bruera E, Higginson I, Payne S (2007) *Research Methods in Palliative Care*. Oxford: Oxford University Press, Ch.10, 163-179.
- Shell J (2008) Sexual issues in the palliative care population. *Seminars in Oncology Nursing*, 24(2), 131-134.
- Sherman B (1998) *Sex, Intimacy and Aged Care*. London: Jessica Kingsley Publishers.
- Shope D F (1975) *Interpersonal Sexuality*. Philadelphia: W B Saunders.
- Silverman H (1987) *Inscriptions: Between Phenomenology and Structuralism*. New York: Routledge Kegan Paul.
- Silverstein C and Picano F (2004) *The Joy of Gay Sex*. New York: Harper Resource.
- Sloan R (2002) Living a life-sustained-by-medical technology: dialysis is killing *me*. In: Diekelmann N (Ed.) *First, Do No Harm: Power, Oppression and Violence in Healthcare*. Madison, Wisconsin: The University of Wisconsin Press, Ch.3, 118-163.
- Smith B (1999) Ethical and methodological benefits of using a reflexive journal in hermeneutic-phenomenologic research. *Journal of Nursing Scholarship*, 31(4), 359-363.
- Smith D (1989) Sexual rehabilitation of the cancer client. *Cancer Nursing*, 12(1), 10-15.
- Smith D and Babaian R (1992) The effects of treatment for cancer on male fertility and sexuality. *Cancer Nursing*, 15(4), 271-275.
- Smythe E (2011) From beginning to end: how to do hermeneutic interpretive phenomenology. In: Thomson G, Dykes F, Downe S (Eds.) *Qualitative Research in Midwifery and Childbirth: Phenomenological Approaches*. London: Routledge, Ch.3, 35-55.
- Smythe E, Ironside P, Sims S, Swenson M, Spence D (2008) Doing Heideggerian hermeneutic research: a discussion paper. *International Journal of Nursing Studies*, 45(9), 1389-1397.
- Smythers R (2008) *Sex Tips for Husbands and Wives from 1894*. Chichester: Summersdale Publishers. [First published in 1894]

Social Policy Research Unit, University of York (2000) *Surveying outcomes of equipment and adaptations*. Available at:

<http://www.york.ac.uk/inst/spru/pubs/rworks/nov2000outc6.pdf> (Accessed on 13th May 2011)

Southard N and Keller J (2009) The importance of assessing sexuality: a patient perspective. *Clinical Journal of Oncology Nursing*, 13(2), 213-217.

Spiegelberg H (1982) *The Phenomenological Movement: A Historical Introduction*, (3rd edition). The Hague: Martinus Nijhoff.

Stanford J, Feng Z, Hamilton A, Gilliland F, Stephenson, Eley W, Albertsen P, Harlan L, Potosky A (2000) Urinary and sexual function after radical prostatectomy for clinically localized prostate cancer: the prostate cancer outcomes study. *The Journal of the American Medical Association*, 283(3):354-360.

Stausmire J (2004) Sexuality at the end of life. *American Journal of Hospice and Palliative Care*, 21(1), 33-39.

Stead M, Brown J, Fallowfield L, Selby P (2003) Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer Nursing*, 88(5), 666-671.

Steinman J (2006) The future ain't what it used to be. Sung by Meatloaf: *Bat out of Hell III: The Monster is Loose*. Mercury Records Ltd [Audio CD]

Steinman J (1989) The future ain't what it used to be. Sung by Pandora's Box: *Original Sin*. Virgin [Record album]

Steinman J (1977) Paradise by the dashboard light. Sung by Meatloaf: *Bat out of Hell*. Epic Records [Record album]

Stenstad G (2006) *Transformations: Thinking after Heidegger*. Madison, Wisconsin: The University of Wisconsin Press.

Stonewall (no date) *History of lesbian, gay and bisexual equality*. Available at:

http://www.stonewall.org.uk/at_home/history_of_lesbian_gay_and_bisexual_equality/default.asp (Accessed on 12th September 2011)

- Stroebe M and Schut H (2010) The dual process model of coping with bereavement: a decade on. *Journal of Death and Dying*, 61(4), 273-290.
- Stroebe M and Schut H (2001) Meaning making in the dual process model of coping with bereavement. In: Neimeyer R (Ed.) *Reconstruction of the Experience of Loss*. Washington: American Psychological Association, Ch.3, 55-73.
- Stroebe M and Schut H (1999) The dual process model of coping with bereavement: rationale and description. *Death Studies*, 23(3), 197-224.
- Summerville P and McKenna K (1998) Sexuality education and counselling for individuals with a spinal cord injury: implications for occupational therapy. *British Journal of Occupational Therapy*, 61(6), 275-279.
- Sweeney A, Harrington A, Button D (2007) Suprapubic catheters ~ a shared understanding, from the other side looking in. *Journal of Wound, Ostomy and Continence Nursing*, 34(4), 418-424.
- Talbot K and Marsden R (2008) *Motor Neuron Disease: The Facts*. Oxford: Oxford University Press.
- Talbot K, Turner R, Marsden R, Botell R (2010) *Motor Neuron Disease: A Practical Manual*. Oxford: Oxford University Press.
- Taylor B (2012a) *'I don't want last time to be the last time': The meaning of sex in life-limiting illness*. Poster presentation at 7th World Research Congress of the European Association for Palliative Care, Trondheim. 7th-9th June.
- Taylor B (2012b) *Sexuality at end of life: The silent bedfellow*. Oral presentation at 9th Palliative Care Congress, Newcastle. 16th March.
- Taylor B (2011a) The impact of assistive equipment on intimacy and sexual expression. *British Journal of Occupational Therapy*, 74(9), 435-442.
- Taylor B (2011b) *Addressing issues of sexuality in terminal disease*. Keynote presentation at 22nd International Symposium on ALS/MND, Sydney. 30th November.
- Taylor B (2011c) *Talking about sexuality and intimacy: overcoming the barriers*. Workshop at 22nd International Symposium on ALS/MND, Sydney. 1st December.

- Taylor B (2010a) *Unstructured or Semi-structured interviews in phenomenological research: does it really matter?* Oral presentation at Qualitative Research Methods conference, Bournemouth. 7th September.
- Taylor B (2010b) *The impact of equipment on relationships: lessons for practice.* Oral presentation at MND Allied Professionals' Forum, Florida. 10th December.
- Taylor B (2010c) *"The doctor said MND wouldn't affect my sexuality" ... but it has.* Oral presentation at 21st International Symposium on ALS/MND, Florida. 12th December.
- Taylor B (2007) Does favouritism play a part in bed allocation in hospices? *European Journal of Palliative Care*, 14(4), 148-151.
- Taylor B (1995) Gender-power relations and safer sex negotiation. *Journal of Advanced Nursing*, 22(4), 687-693.
- Taylor B and Davis S (2007) The extended PLISSIT model for addressing the sexual wellbeing of individuals with an acquired disability or chronic illness. *Sexuality and Disability*, 25(3), 135-139.
- Taylor B and Davis S (2006) Using the extended PLISSIT model to address sexual healthcare needs. *Nursing Standard*, 21(11), 35-40.
- Taylor B and de Vocht H (2011) Interviewing separately or as couples? Considerations of Authenticity of Method. *Qualitative Health Research*, 21(11), 1576-1587.
- Taylor P (1983) Understanding sexuality in the dying patient. *Nursing*, 13(4), 54-55.
- Terry W, Olson L, Ravenscroft P, Wilss L, Boulton-Lewis G (2006) Hospice patients' views on research in palliative care. *Internal Medicine Journal*, 36(7), 406-413.
- The Bible Societies (1976) *Good News Bible*. Glasgow: William Collins Sons and Co Ltd.
- The Rowan's Hospice (no date) *Hospice Movement*. Available at:
<http://www.rowanhospice.co.uk/index.php?id=13> (Accessed on 19th May 2012)
- Thomas S and Pollio H (2002) *Listening to Patients: A Phenomenological Approach*. New York: Springer Publishing Company.

- Thompson J (1990) Hermeneutic inquiry. In: Moody E (Ed.) *Advancing Nursing Science Through Research*. Volume 2, Newbury Park, California: Sage, Ch.7, 223-286.
- Todres L and Holloway I (2010) Phenomenological Research. In: Gerrish K and Lacey A (Eds.) *The Research Process in Nursing* (6th edition). Oxford: Blackwell Publishing Ltd.
- Toombs K (2008) *Living at the Boundary: Healing and Incurable Illness*. 2008 Medical Humanities Lecture, Baylor University. 15th October. Available at: <http://www.baylor.edu/content/services/document.php/74627.pdf> (Accessed on 9th April 2012)
- Toombs K (1995) Sufficient unto the day: a life with multiple sclerosis. In: Toombs K, Barnard D, Carson R (Eds.) *Chronic Illness: From Experience to Policy*. Bloomington: Indiana University Press, Ch.1, 3-23.
- Toombs K, Barnard D, Carson R (1995) Preface. In: Toombs K, Barnard D, Carson R (Eds.) *Chronic Illness: From Experience to Policy*. Bloomington: Indiana University Press, ix-xiv.
- van de Velde T (1930) *Ideal Marriage: Its Physiology and Technique*. New York: Random House Inc. [First published in 1926]
- van Manen M (1997) From meaning to method. *Qualitative Health Research*, 7(3), 345-369.
- van Manen M (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. New York: State University of New York Press.
- van Ooijen E and Charnock A (1994) *Sexuality and Patient Care: A Guide for Nurses and Teachers*. London: Chapman Hall.
- Veyne P (1985) Homosexuality in ancient Rome. In: Ariès P and Béjin A (Eds.) *Western Sexuality: Practice and Precept in Past and Present Times*. Oxford: Basil Blackwell Ltd, Ch.3, 26-35.
- Vitrano V, Catania V, Mercadante S (2011) Sexuality in patients with advanced cancer: a prospective study in a population admitted to an acute pain relief and palliative care unit. *American Journal of Hospice and Palliative Medicine*, 28(3), 198-202.

- Wallace M and Safer M (2009) Hypersexuality among cognitively impaired older adults. *Geriatric Nursing*, 30(4), 230-237.
- Wallis N (2007) First person: my lifelong desire. *The Guardian*. 14th January. Available at: <http://www.guardian.co.uk/society/2007/jan/15/health.socialcare> (Accessed on 20th September 2011)
- Walton J and Madjar I (1999) Phenomenology and nursing. In: Madjar I, Walton J (Eds.) *Nursing and the Experience of Illness: Phenomenology in Practice*. London: Routledge, Ch.1, 1-15.
- Wasner M, Bold U, Vollmer T, Borasio GD (2004) Sexuality in patients with amyotrophic lateral sclerosis and their partners. *Journal of Neurology*, 251(4), 445-448.
- Wasow M (1977) Human sexuality and terminal illness. *Health and Social Work*, 2(2), 104-121.
- Watson M, Lucas C, Hoy A, Back I (2005) *Oxford Handbook of Palliative Care*. Oxford: Oxford University Press.
- Webb C (1985) *Sexuality, Nursing and Health*. Chichester: John Wiley and Sons Ltd.
- Webster C and Heath H (2002) Sexuality and people with disability or chronic illness. In: Heath H, White I (Eds.) *The Challenge of Sexuality in Health Care*. Oxford: Blackwell Science Ltd, Ch.14, 211-225.
- Weeks J (1986) *Sexuality*. London: Routledge.
- Weiss R (1991) The attachment bond in childhood and adulthood. In: Murray-Parkes C, Stevenson-Hinde J, Marris P (Eds.) *Attachment Across the Life Cycle*. London: Routledge, Ch.4, 66-76.
- Wellings K, Branigan P, Mitchell K (2000) Discomfort, discord and discontinuity as data: using focus groups to research sensitive topics. *Culture, Health and Sexuality*, 2(3), 255-267.
- Wellings K, Nanchahal K, Macdowall W, McManus S, Erens B, Mercer C, Johnson A, Copas A, Korovessis C, Fenton K, Field J (2001) Sexual behaviour in Britain: Early heterosexual experience. *Lancet*, 358(9296), 1843-1850.

- Wells P (2002) No sex please, I'm dying. A common myth explored. *European Journal of Palliative Care*, 9(3), 119-122.
- Wenger G (2002) Interviewing older people. In: Gubrium J, Holstein J (Eds.) *Handbook of Interview Research: Context and Method*. London: Sage Publications Ltd, Ch.13, 259-278.
- White K (2003) Sexuality and body image. In: O'Connor M, Aranda S (Eds.) *Palliative Care Nursing: A Guide to Practice* (2nd edition). Abingdon: Radcliffe Medical Press. Ch.17, 245-256.
- Wickett A (1986) Sex and the terminally ill patient. *The Euthanasia Review*, 1(2), 79-84.
- Wilkie (2001) Ethical issues in qualitative research in palliative care. In: Field D, Clark D, Corner J, Davis C (Eds.) *Researching Palliative Care*. Buckingham: Open University Press, Ch.7, 67-74.
- Williams C and Heikes E (1993) The importance of researcher's gender in the in-depth interview: evidence from two case studies of male nurses. *Gender and Society*, 7(2), 280-291.
- Williams S and Bendelow G (1998) *The Lived Body: Sociological Themes, Embodied Issues*. London: Routledge.
- Wilmoth M (2001) The aftermath of breast cancer: an altered sexual self. *Cancer Nursing*, 24(4), 278-286.
- Wimpenny P and Gass J (2000) Interviewing in phenomenology and grounded theory: is there a difference? *Journal of Advanced Nursing*, 31(6), 1485-1492.
- Wood F (1991) The meaning of caregiving. *Rehabilitation Nursing*, 16(4), 195-198.
- Woodhouse J and Baldwin M (2008) Dealing sensitively with sexuality in a palliative care context. *British Journal of Community Nursing*, 13(1), 20-25.
- World Health Organisation (2001) *International Classification of Functioning, Disability and Health: Short Version*. Geneva: World Health Organisation.
- World Health Organisation (1998) The World Health Organisation quality of life assessment (WHO-QOL): development and general psychometric properties. *Social Science and Medicine*, 46(12), 1569-1585.

Wrathall M (2005) *How to Read Heidegger*. London: Granta Books.

Wright P and Hogan N (2008) Grief theories and models: Applications to hospice nursing practice. *Journal of Hospice and Palliative Nursing*, 10(6), 350-356.

Yaniv H (1995) Sexuality of cancer patients – a palliative approach. *European Journal of Palliative Care*, 2(2), 69-72.

Young W (1960) Lawrence Unbound. *The Guardian*. 4th November. Available at: <http://www.guardian.co.uk/media/from-the-archive-blog/2011/may/29/lady-chatterley-trial-f-k-1960> (Accessed on 18th September 2011)

Yurek D, Farrar W, Andersen B (2000) Breast cancer surgery: comparing surgical groups and determining individual differences in postoperative sexuality and body change stress. *Journal of Consulting and Clinical Psychology*, 68(4), 697-709.

Zitzelsberger H (2004) Concerning technology: thinking with Heidegger. *Nursing Philosophy*, 5(3), 242-250.

Appendices

Appendix 1 Participant invitation letter⁷¹

Printed on Oxford Brookes University headed paper

Bridget Taylor
PhD Research Student

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Date inserted

Dear patient of Dr [name]

Dr [name] has given permission for me to invite you take part in a research study. This study is currently taking place in several organisations, including [name of organisation].

As you will see from the attached research information sheet, we are interested in the experiences of both patients and partners of patients who are living with life-limiting illnesses. Research that has been carried out so far has explored the effects of diagnosis or treatment on individuals' sexuality. It has not considered the experiences of people living with life-limiting illnesses. This study explores the impact of living with a life-limiting illness on individuals' and their partners' sexuality and expression of intimacy. The formal research question is:

What are the experiences of patients and partners of patients who have life-limiting illnesses in relation to sexuality and intimacy?

Whilst sexuality and intimacy are private and sensitive topics, it is important for healthcare professionals to understand the issues people face to ensure that they give appropriate support and information about this important aspect of people's lives. We hope that the results of this study will help to inform healthcare professionals who provide care to those in similar circumstances to yourself and will ultimately improve the experiences of others with life-limiting illnesses.

⁷¹ Names of individuals and organisations have been removed to maintain anonymity.

This research is being conducted for a PhD at Oxford Brookes University. It has been approved to take place by Oxford Brookes University research ethics committee, the [named] NHS Trust ethics committee, and the National Research Ethics Service.

I would be grateful if you would be prepared to take the time to read the enclosed research information sheet and to consider whether or not you would like to take part in this research. I would also be grateful if you would show this letter to your partner / spouse (if relevant), and give them the information sheet for partners / spouse, so that they can also decide whether or not they would like to take part. It is not a requirement of the study that patients are married or in a partnered relationship. It is also not a requirement that both the patient and their partner / spouse take part.

If you have any questions about the study or would like to discuss any aspect of the information sheet further, please contact me, the researcher, by post, by phone or by email as indicated.

Once you have had the opportunity to consider your decision, please complete the reply slip at the end of this letter and return it in the stamped, addressed envelope provided. One reply slip is provided for patients and another one for partners. Alternatively, you could contact me by email or by phone to inform me of your decision. If you and/or your partner do not wish to take part, completing the last section of the reply slip anonymously would be helpful. This is entirely optional.

Thank you for considering this request to take part in this research study.

Yours sincerely

Bridget Taylor

Professor Mary Boulton

Dr Jane Appleton

PhD Research Student

Director of Studies

Research Supervisor

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Appendix 2 Participant information sheet for patients⁷²

Printed on Oxford Brookes University headed paper

Information about the research for patients

Date inserted

Study Title: What are the experiences of patients and partners of patients who have life-limiting illnesses in relation to sexuality and intimacy?

You are being invited to take part in a research study being conducted as a PhD research project at Oxford Brookes University. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, you can contact us to discuss it further.

Thank you for reading this.

What is the purpose of the study?

We are interested in understanding the impact of life-limiting illness on the expression of intimacy and sexuality by patients and partners of patients. Whilst this is a private and sensitive topic, it is important for healthcare professionals to understand the issues individuals face, so that they can provide appropriate information and support.

Research that has been carried out so far has focussed on the effects of diagnosis or treatment on individuals' sexuality. It has not considered the experiences of people living with life-limiting illnesses. This study explores the impact of living with a life-limiting illness on individuals' and partners' sexuality and expression of intimacy.

⁷² Names of individuals and organisations have been removed to maintain anonymity.

Information provided by those participating would be used to inform healthcare professionals who provide care to people in similar circumstances to you. It is anticipated that the study would take 2-3 years for the researcher to complete.

Why have I been invited to participate?

You have been sent this invitation to participate because you are receiving care from [name of organisation]. Dr [name of consultant] has given permission for you to be invited.

We would like to interview 20-25 patients, as well as 20-25 partners of patients. Our plan is to interview as broad a range of people as possible. This includes adults of all ages, people from different ethnic backgrounds, with a range of diagnoses and different sexual identities.

It is not a requirement of the study that patients are married or in a partnered relationship. It is also not a requirement of the study that both the patient and their partner / spouse take part. Patients and partners of patients who choose to take part would be interviewed separately. If you are married or in a partnered relationship, we also ask that you show the invitation letter to your husband/wife/partner to read, as well as the information sheet titled, 'Information about the research for patients' partners or spouse'. They will then be able to decide whether they would like to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. Participation is voluntary and your care or treatment would not be affected in any way, whether or not you take part.

If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time, without giving a reason.

Your decision not to take part in the study, or your decision to withdraw from the study at any time will not affect your care in any way and no one else would be told of your decision.

What is involved if I decide to take part?

If you agree to take part in this study, you would be asked to participate in two interviews,

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1-2 weeks apart. Each interview would last approximately 1 hour. The interviews would be arranged at a convenient time and would take place in a private room at a mutually convenient location. The first interview could be arranged on the day of your next clinic appointment, in order to minimise any inconvenience to you, or could be in your own home. The interviews would be tape-recorded to ensure an accurate record of the conversation is obtained and would be conducted by Bridget Taylor. Bridget is a registered nurse, working as a staff nurse at [named] hospice. She is also a senior lecturer in sexual health at [named] University.

Before the first interview starts, you would have an opportunity to ask any questions. If you were happy to continue, you would be asked to sign a consent form. You would be given a copy of this to keep.

During the interviews, you would be asked to answer the questions asked of you in as full and honest a manner as you can. You would be asked to talk about your current illness and how it affects you in your everyday life. You would be asked to describe how this affects your sexuality or ways in which you express intimacy, and whether this has changed since before you were ill. You would also be asked whether you have any advice or recommendations for healthcare professionals. The purpose of the second interview is to elaborate on themes discussed in the first interview. At the end of the interviews, Bridget would give you the opportunity to debrief and ask any questions.

If you agree to take part in this study and, during the interview, feel tired, unwell, or do not wish to continue further, the interview would be stopped. If you wished to, you would have the opportunity to continue on another occasion. If you do decide to take part, you are still free to withdraw at any time, without giving a reason.

What are the possible disadvantages and risks of taking part?

We do not anticipate that there are any risks associated with taking part in this study. If it does raise issues that you would like to discuss further, you would be free to discuss them with the healthcare professionals involved in your care. If you would like, the researcher, Bridget Taylor, will provide you with information and details of specialist sources of support and advice.

If you choose to participate, the interviews would take place at a mutually convenient location. If you incur any additional travel expenses, these would be reimbursed.

What are the possible benefits of taking part?

Taking part in this study is unlikely to benefit you directly. However, the information gained will further our understanding of these aspects of individuals' lives. We hope that the information gained will help to inform healthcare professionals who provide care to those in similar circumstances to yourself and will ultimately improve the experiences of others with life-limiting illnesses.

Will what I say in this study be kept confidential?

Yes. Your confidentiality would be maintained throughout. You would only be identified by a code on all tapes and records. The researcher, Bridget Taylor, would be the only person who has access to this code. The audiotapes would be kept in a locked cupboard and Bridget Taylor would hold the key. A secretary who has signed a confidentiality clause would transcribe these anonymised tapes. Bridget and her supervisors (Professor Mary Boulton and Dr Jane Appleton) would be the only other people to have access to the data.

When the results of the study are written-up or published, your identity would not be disclosed and all direct quotations would be anonymised. In accordance with Oxford Brookes University's policy on academic integrity, the data produced in the course of this research will be retained for five years after the completion of the study. This information will be kept securely in a locked cupboard.

Bridget Taylor would not be at liberty to inform any individual whether or not their partner / spouse had also taken part in the study. No information shared by one individual would be disclosed to their partner.

If you agree to take part, with your permission, your GP would be informed of your participation in this research. This is a recommendation of the local research ethics committee. None of the information that you give would be shared by the researcher with your GP or any other person involved in your care. It is up to you whether you would want to discuss any of the issues raised with anyone involved in your care.

What should I do if I want to take part?

If you would like to take part in this study, please return the reply-slip attached to the letter of invitation (one has been provided for patients and one for partners of patients) and send it to Bridget Taylor in the stamped, addressed envelope provided. Bridget will then contact you to arrange a convenient time and location for the first interview to take place.

If you have further questions that you would like to ask before you reach a decision, Bridget would be happy to discuss these with you, either by telephone or by email. Her contact details are at the end of this information sheet.

What will happen to the results of the research study?

When the results of the study are written-up or published, your identity would not be disclosed in any publication and all direct quotations would be anonymised. A copy of the final report would be available for any participant who wishes to see it. This will be available from Bridget. It is anticipated that this would be completed in 2010. The results of the study would be available to the managers of the organisations involved, would be published in professional journals and presented at relevant healthcare conferences. The study findings also contribute to the award of a PhD at Oxford Brookes University for the chief investigator (Bridget Taylor) and will be presented in a thesis that is retained by the university library.

Who is organising and funding the research?

This research is being conducted by Bridget Taylor as a PhD project. Bridget is a senior lecturer in sexual health at [named] university and is also a staff nurse at [named] hospice. The study is partly funded by a research grant from the Oxfordshire Health Services Research Committee.

Who has reviewed the study?

Ethical approval to undertake this study has been given by Oxford Brookes University research ethics committee, the National Research Ethics Service and the [named organisation's] Evidence Based Practice Group / Clinical Governance Committee.

What if there is a problem?

If you have any concerns about the way in which the study has been conducted, please

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contact the academic supervisors (Professor Mary Boulton and Dr Jane Appleton at Oxford Brookes University) on 01865 482600. If you would like to discuss these concerns further, you can do this by contacting Hazel Abbott, Research Ethics Lead on heabbott@brookes.ac.uk or by telephoning 01865 482639.

Contact for Further Information

If you would like any further information about the study, have any questions, or wish to discuss it further, please do not hesitate to contact the researcher, Bridget Taylor.

- Name:** Bridget Taylor, PhD Research Student
- Address:** School of Health & Social Care, Oxford Brookes University
Jack Straw's Lane, Marston, Oxford. OX3 0FL
- Email:** bmtaylor@brookes.ac.uk
- Tel:** 01865 482655 (an answerphone will take messages)

If you would like to discuss whether or not to participate in this study with an independent person, you may telephone the Patient Advisory Liaison Service at [named] Hospital on ** or by email on **

Thank you for taking the time to read this information sheet.

Bridget Taylor	Professor Mary Boulton	Dr Jane Appleton
PhD Research Student	Director of Studies	Research Supervisor

Appendix 3 Participant information sheet for partners⁷³

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Information about the research for patients' partners or spouse

Date inserted

Study Title: What are the experiences of patients and partners of patients who have life-limiting illnesses in relation to sexuality and intimacy?

You are being invited to take part in a research study being conducted as a PhD research project at Oxford Brookes University. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, you can contact us to discuss it further.

Thank you for reading this.

What is the purpose of the study?

We are interested in understanding the impact of life-limiting illness on the expression of intimacy and sexuality by patients and partners of patients. Whilst this is a private and sensitive topic, it is important for healthcare professionals to understand the issues individuals face, so that they can provide appropriate information and support.

Research that has been carried out so far has focussed on the effects of diagnosis or treatment on individuals' sexuality. It has not considered the experiences of people living with life-limiting illnesses. This study explores the impact of living with a life-limiting illness on individuals' and partners' sexuality and expression of intimacy.

⁷³ Names of individuals and organisations have been removed to maintain anonymity.

Information provided by those participating would be used to inform healthcare professionals who provide care to people in similar circumstances to you. It is anticipated that the study would take 2-3 years for the researcher to complete.

Why have I been invited to participate?

You have been given this invitation to participate because your partner / spouse is receiving care from [name of organisation]. Dr [name of consultant] has given permission for them to be invited to take part in the study.

We would like to interview 20-25 partners of patients, as well as 20-25 patients. Our plan is to interview as broad a range of people as possible. This includes adults of all ages, people from different ethnic backgrounds, with a range of diagnoses and different sexual identities. It is not a requirement of the study that both the patient and their partner / spouse take part. Patients and partners of patients who choose to take part would be interviewed separately.

Do I have to take part?

It is up to you to decide whether or not to take part. Participation is voluntary and neither yours nor your partner's / spouse's care or treatment would be affected in any way, whether or not you take part.

If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time, without giving a reason.

Your decision not to take part in the study, or your decision to withdraw from the study at any time will not affect your care in any way and no one else would be told of your decision.

What is involved if I decide to take part?

If you agree to take part in this study, you would be asked to participate in two interviews, 1-2 weeks apart. Each interview would last approximately 1 hour. The interviews would be arranged at a convenient time and would take place in a private room at a mutually convenient location. The first interview could be arranged on the day of your partner's / spouse's next clinic appointment, in order to minimise any inconvenience to you, or could be in your own home. The interviews would be tape-recorded to ensure an accurate record of the conversation is obtained and would be conducted by Bridget Taylor. Bridget is a

registered nurse, working as a staff nurse at [named hospice]. She is also a senior lecturer in sexual health at [named university].

Before the first interview starts, you would have an opportunity to ask any questions. If you were happy to continue, you would be asked to sign a consent form. You would be given a copy of this to keep.

During the interviews, you would be asked to answer the questions asked of you in as full and honest a manner as you can. You would be asked to talk about your partner's current illness and how it affects you in your everyday life. You would be asked to describe how this affects your sexuality or ways in which you express intimacy, and whether this has changed since before your partner / spouse was ill. You would also be asked whether you have any advice or recommendations for healthcare professionals. The purpose of the second interview is to elaborate on themes discussed in the first interview. At the end of the interviews, Bridget would give you the opportunity to debrief and ask any questions.

If you agree to take part in this study and, during the interview, feel tired, unwell, or do not wish to continue further, the interview would be stopped. If you wished to, you would have the opportunity to continue on another occasion. If you decide to take part, you are still free to withdraw at any time, without giving a reason.

What are the possible disadvantages and risks of taking part?

We do not anticipate that there are any risks associated with taking part in this study. If it does raise issues that you would like to discuss further, you would be free to discuss them with the healthcare professionals involved in your care. If you would like, the researcher, Bridget Taylor, will provide you with information and details of specialist sources of support and advice.

If you choose to participate, the interviews would take place at a mutually convenient location. If you incur any additional travel expenses, these would be reimbursed.

What are the possible benefits of taking part?

Taking part in this study is unlikely to benefit you directly. However, the information gained will further our understanding of these aspects of individuals' lives. We hope that the information gained will help to inform healthcare professionals who provide care to those in similar circumstances to yourself and will ultimately improve the experiences of others living with life-limiting illnesses.

Will what I say in this study be kept confidential?

Yes. Your confidentiality would be maintained throughout. You would only be identified by a code on all tapes and records. The researcher, Bridget Taylor, would be the only person who has access to this code. The audiotapes would be kept in a locked cupboard and Bridget Taylor would hold the key. A secretary who has signed a confidentiality clause would transcribe these anonymised tapes. Bridget and her supervisors (Professor Mary Boulton and Dr Jane Appleton) would be the only other people to have access to the data.

When the results of the study are written-up or published, your identity would not be disclosed and all direct quotations would be anonymised. In accordance with Oxford Brookes University's policy on academic integrity, the data produced in the course of this research will be retained for five years after the completion of the study. This information will be kept securely in a locked cupboard.

Bridget Taylor would not be at liberty to inform any individual whether or not their partner / spouse had also taken part in the study. No information shared by one individual would be disclosed to their partner. None of the information that you give would be shared by the researcher with anyone involved in either your or your partner's care. It is up to you whether you would want to discuss any of the issues raised with anyone involved in your care.

What should I do if I want to take part?

If you would like to take part in this study, please return the reply-slip for partners of patients (attached to the invitation letter) and send it to Bridget Taylor in the stamped, addressed envelope provided. Bridget will then contact you to arrange a convenient time and location for the interviews to take place.

If you have further questions that you would like to ask before you reach a decision, Bridget would be happy to discuss these with you, either by telephone or by email. Her contact details are at the end of this information sheet.

What will happen to the results of the research study?

When the results of the study are written-up or published, your identity would not be disclosed in any publication and all direct quotations would be anonymised. A copy of the final report would be available for any participant who wishes to see it. This will be available from Bridget. It is anticipated that this would be completed in 2010. The results of

the study would be available to the managers of the organisations involved, would be published in professional journals and presented at relevant healthcare conferences.

The study findings also contribute to the award of a PhD at Oxford Brookes University for the chief investigator (Bridget Taylor) and will be presented in a thesis that is retained by the university library.

Who is organising and funding the research?

This research is being conducted by Bridget Taylor as a PhD project. Bridget is a senior lecturer in sexual health at [named university] and is also a staff nurse at [named hospice]. The study is partly funded by a research grant from the Oxfordshire Health Services Research Committee.

Who has reviewed the study?

Ethical approval to undertake this study has been given by Oxford Brookes University research ethics committee, the National Research Ethics Service and the [named organisation's] Evidence Based Practice Group / Clinical Governance Committee.

What if there is a problem?

If you have any concerns about the way in which the study has been conducted, please contact the academic supervisors (Professor Mary Boulton and Dr Jane Appleton at Oxford Brookes University) on 01865 482600. If you would like to discuss these concerns further, you can do this by contacting Hazel Abbott, Research Ethics Lead on heabbott@brookes.ac.uk or by telephoning 01865 482639.

Contact for Further Information

If you would like any further information about the study, have any questions, or wish to discuss it further, please do not hesitate to contact the researcher, Bridget Taylor.

Name: Bridget Taylor, PhD Research Student

Address: School of Health & Social Care, Oxford Brookes University

Jack Straw's Lane, Marston, Oxford. OX3 0FL

Email: bmtaylor@brookes.ac.uk

Tel: 01865 482655 (an answerphone will take messages)

If you would like to discuss whether or not to participate in this study with an independent person, you may telephone the Patient Advisory Liaison Service at [named] Hospital on ** or by email on **

Thank you for taking the time to read this information sheet.

Bridget Taylor

Professor Mary Boulton

Dr Jane Appleton

PhD Research Student

Director of Studies

Research Supervisor

Appendix 4 Summary of feedback from affected communities

31st December 2007

Cancer Services Patient and Carer Panel

This group agreed to review the invitation letter and information sheets for potential participants. I did not receive any feedback on version 01 of the documents that I sent for review.

Patients with life-limiting cancer

Two patients reviewed the invitation letter and participant information sheets for patients and partners.

1. Individuals are not obliged to take part and can withdraw at any time. This was considered to be clearly stated and emphasised appropriately.
2. One patient felt the wording 'life-limiting' could be gentler, stating: "It's bad enough knowing, without being told it". 'Serious illness' was suggested as alternative wording. It is notable that this individual still expressed a wish to take part in the study, though was reminded that the purpose of the discussions at this point were for feedback and guidance, not for the purpose of recruiting.
Action: This feedback confirmed the importance of the inclusion criterion: 'Patients are aware that they have a life-limiting illness.' As none of the other individuals consulted considered this wording in the invitation letter and information sheets to be upsetting in any way (see below), a consensus view was taken. It was decided to change the research question from 'patients who have a life-limiting illness' to 'patients who have life-limiting illnesses.'
3. Individuals felt it was clearly stated when the results of the study would be available. One patient stated: "Most of us wouldn't be alive then, but at least people would know they wouldn't see the results before they decide if they want to take part".

Patients with motor neurone disease

Two patients and one partner of a patient discussed the study design and conduct, and also reviewed the invitation letter and participant information sheets for patients and partners. They were also asked to give their views on the inclusion and exclusion criteria, and the leaflet itemising sources of information and support.

4. Individuals are not obliged to take part and can withdraw at any time. This was described as being clearly stated and emphasised. It was felt important that individuals' care would not be affected in anyway. This was also described as being clearly stated.
5. Two individuals felt that some of the information provided in the information sheets was repetitive. This was described as "off-putting" for the reader.
Action: Information sheets altered to minimise repetition, whilst still complying with NRES requirements.
6. Individuals felt that some partnered pairs may wish to participate. They felt confidentiality and the interviewing of individuals separately is clearly stated.
7. Individuals felt that none of the wording was upsetting or would cause offence. When asked explicitly about the term 'life-limiting', none of the individuals had any concerns about this. For example, one patient who had only been diagnosed 18 months stated: "It's something we all have to come to terms with". These individuals supported the inclusion and exclusion criteria, agreeing that it is important that those who are invited to take part are aware that they have a life-limiting condition
8. The reason for tape-recording the interviews was considered unclear.
Action: Information sheet altered to provide this information.
9. The purpose of the 2nd interview was considered unclear.
Action: Information sheet altered to provide this information.
10. It was considered unclear why the participant's GP is to be informed.
Action: Information sheet altered to provide this information.

11. One individual felt it was a good idea to give people the chance of saying (anonymously on the invitation letter reply slip) why they did not wish to take part in the study. "It may be for all sorts of reasons".

Action: No changes made.

12. The information sheet itemising sources of information and support was considered to be a "useful resource". The way it would be offered to participants was considered effective in ensuring that its content would not cause offence. One individual suggested that details of contraceptive services also be added.

Action: To include this could have the potential of causing distress to participants with a very limited life expectancy. Therefore, no changes have been made.

Appendix 5 Ethics approval from Oxford Brookes University

OXFORD
BROOKES
UNIVERSITY

School of Health and Social Care

Hazel Abbott
Research Ethics Lead

MR1/39 Marston Road Campus
Jack Straws Lane Marston Oxford OX3 0FL
t. +44 (0)1865 482639 f. +44 (0)1865 482775
heabbott@brookes.ac.uk
www.brookes.ac.uk

To: National Research Ethics Service/
Research and Development/
Local Research Ethics Committee

18th December 2007

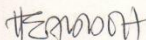
To whom it may concern,

Re. A qualitative study to identify the meaning of sexuality and intimacy in life-limiting illness

I am writing to confirm that Oxford Brookes University is accepting the role of Sponsor for the above research project. This is in accordance with the role and responsibilities of Sponsor, as laid out in the Research Governance Framework for Health and Social Care (2005).

Bridget Taylor, the Chief Investigator, is studying for a PhD at Oxford Brookes University. Professor Mary Boulton is the Director of Studies for this student and will supervise the research.

Yours faithfully,



Hazel Abbott
Research Ethics Lead

cc: Sarah Taylor, Research and Business Development Office
cc. Professor Mary Boulton, Director of Studies

Appendix 6 Ethics approval from National Research Ethics Service (NRES)



National Research Ethics Service Milton Keynes Local Research Ethics Committee

Room 7B, PGEC
Milton Keynes Hospital Site
Standing Way
Eaglestone
Milton Keynes
MK6 5LD

01908 243750 (tele/fax)

06 February 2008

Ms Bridget M Taylor
PhD Research Student
Oxford Brookes University
Jack Straws Lane
Marston
Oxford OX3 0FL

Dear Ms Taylor

Full title of study: Qualitative study to identify the meaning of sexuality and intimacy in life-limiting illness
REC reference number: 08/H0603/3

The Research Ethics Committee reviewed the above application at the meeting held on 30 January 2008. Thank you for attending to discuss the study.

Ethical opinion

Bridget when you attended the meeting you gave an overview of your study and then answered questions from the committee which are summarised below:

- The committee stated that the paper you researched on this subject from Canada had included patients with a life limiting illness. You are going to try and recruit a different range of people not just heterosexuals and their partners and you were asked to explain how you were going to do this.
You replied that if you find from initial checking of your participants on a weekly basis that you have recruited only heterosexuals (including partners), you are going to ask the Registrar/Specialist Nurse at their next clinic to check again the inclusion/exclusion criteria and to make sure they invite "other" groups into the study and hopefully this will ensure they are not bringing in any bias. You did think it was going to be difficult to recruit groups other than heterosexuals. If the study reveals important issues, then you may need to target specific groups, including those who do not speak English as well.
- You advised that you will keep the data if a participant isn't able to attend the second interview. You were not sure if this is specifically stated in your PIS but you would check.
- You did already ask potential participants how they would feel if in the PIS you included that you might see them at the Hospice where you work. They were uncomfortable with this being included as they felt this would imply they had already agreed to be admitted into the Hospice. You felt that it raised more concerns than eased worries. If a participant did happen to be admitted to the Hospice you would ensure they understood that no details of their participation in this project would be disclosed.
- You advised that it was appropriate to refer to "their care" on the PIS for partners as various members of the family are involved in the care process.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

- You agreed it could be useful if you were able to correlate pairs of partners views but it is unlikely because there won't be significant numbers and this is simply because of the likelihood of the small numbers of pairs being involved.
- You advised that you had tried to shorten your PIS but you used the pro-forma from the NRES website which incorporated all of this information and although you agree it is long, you felt it is necessary to give the participant all the information in the relevant sections.
- You confirmed you are going to destroy your data after 5 years in a secure and confidential manner.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.5	02 January 2008
Investigator CV	B Taylor	01 September 2007
Protocol	4	31 December 2007
Covering Letter	B Taylor	04 January 2008
Summary/Synopsis	02	19 November 2007
Letter from Sponsor	H Abbott	18 December 2007
Peer Review	E4/SH&SC Form	18 December 2007
Peer Review	H Abbott	18 December 2007
Compensation Arrangements	Form D	18 December 2007
Interview Schedules/Topic Guides	2	25 October 2007
Letter of invitation to participant	3	31 December 2007
GP/Consultant Information Sheets	2	19 November 2007
Participant Information Sheet: Partners	3	31 December 2007
Participant Information Sheet: Patients	3	31 December 2007
Participant Consent Form: Partners	1	31 December 2007
Participant Consent Form: Patients	1	31 December 2007
References	Various x6	
Leaflet	1	19 November 2007
Response	Oxford Brookes Ethics Committee	31 December 2007
Summary-Feedback	&Actions Taken	31 December 2007

Letter	S Candler	14 June 2007
CV Supervisors	Prof M Boulton & Dr J Appleton	31 July 2007

R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final approval from the R&D office before commencing any research procedures.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

- a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
- b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
- e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk.

08/H0603/3	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



Dr J Zachariah
Chair

jos

Appendix 7 NRES substantial amendment approved 13/11/08



National Research Ethics Service

Milton Keynes Research Ethics Committee

Room 7B, PGEC
Milton Keynes Hospital Site
Standing Way
Eaglestone
Milton Keynes
MK6 5LD

01908 243750 (tele/fax)

26 November 2008

Ms Bridget M Taylor
PhD Research Student
Oxford Brookes University
Jack Straws Lane
Marston
Oxford OX3 0FL

Dear Ms Taylor

Study title: Qualitative study to identify the meaning of sexuality and intimacy in life-limiting illness
REC reference: 08/H0603/3
Amendment number: 2
Amendment date: 13 November 2008

The above amendment was reviewed by the sub-committee held on 26 November 2008.

Ethical opinion

The members of the sub-committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	5	04 November 2008
Participant Information Sheet	5 Patient	04 November 2008
Participant Consent Form: Patient	2	04 November 2008
Notice of Substantial Amendment (non-CTIMPs)	2 13/11/2008	13 November 2008
Covering Letter	B Taylor	13 November 2008

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/H0603/3:

Please quote this number on all correspondence

Yours sincerely



Mrs Nicky Searle
Committee Co-ordinator

E-mail: scsha.MiltonKeynesREC@nhs.net

Enclosures List of names and professions of members who were present at the meeting

Copy to: Mrs Hazel Abbott, School of Health and Social Care, Jack Straws Lane

Appendix 8 NRES substantial amendment approved 05/07/09



Milton Keynes Research Ethics Committee

Room 7B, PGEC
Milton Keynes Hospital Site
Standing Way
Eaglestone
Milton Keynes
MK6 5LD

01908 243750 (tele/fax)

16 July 2009

Bridget Taylor
School of Health and Social Care
Oxford Brookes University
Jack Straw's Lane
Marston
Oxford OX3 0FL

Dear Bridget

Study title: Qualitative study to identify the meaning of sexuality and intimacy in life-limiting illness
REC reference: 08/H0603/3
Amendment number: 3
Amendment date: 05 July 2009

The above amendment was reviewed at the meeting of the Committee held on 15 July 2009.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol	6	04 July 2009
Participant Information Sheet	Partners	04 July 2009
Participant Information Sheet	Patients	04 July 2009
Notice of Substantial Amendment (non-CTIMPs)	3	05 July 2009

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

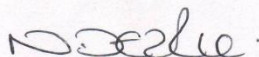
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/H0603/3:	Please quote this number on all correspondence
-------------	--

Yours sincerely



Mrs Nicky Searle
Committee Co-ordinator

E-mail: scsha.MiltonKeynesREC@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Mrs Hazel Abbott, School of Health and Social Care*

Appendix 9 NRES substantial amendment approved 07/02/10



National Research Ethics Service Berkshire Research Ethics Committee

Building L27
University of Reading
London Road
Reading
RG1 5AQ

17 March 2010

Telephone: 0118 918 0551 / 0550
Facsimile: 0118 918 0559

Ms Bridget M Taylor
School of Health & Social Care
Oxford Brookes University
Jack Straws Lane
Marston
Oxford
OX3 0FL

Dear Ms Taylor

Study title: Qualitative study to identify the meaning of sexuality and intimacy in life-limiting illness
REC reference: 08/H0603/3
Amendment number: 7
Amendment date: 07 February 2010

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
CV for Dr Rebecca Sloan		01 January 2010
Letter of invitation to participant	4	07 February 2010
Participant Information Sheet: Patients' partners or spouse	6	07 February 2010
Participant Information Sheet: Patients	6	07 February 2010
Protocol	7	07 February 2010
Notice of Substantial Amendment (non-CTIMPs)	7	07 February 2010
Covering Letter		08 February 2010

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

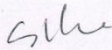
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

08/H0603/3:

Please quote this number on all correspondence

Yours sincerely



Ms Lavenda Lee
Assistant Co-ordinator

E-mail: scsha.berksrec@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Sponsor - Mrs Hazel Abbott, Oxford Brookes University*

This Research Ethics Committee is an advisory committee to South Central Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England

Appendix 10 Consent form

Printed on Oxford Brookes University headed paper

Address for correspondence

Bridget Taylor
PhD Research Student

School of Health & Social Care
Oxford Brookes University
Jack Straws Lane, Marston, Oxford, OX3 0FL
t. +44 (0)1865 482655 f. +44 (0)1865 482775
bmtaylor@brookes.ac.uk

Study Title: What are the experiences of patients and partners of patients who have life-limiting illnesses in relation to sexuality and intimacy?

Please initial boxes

1. I confirm that I have read and understand the information sheet dated 27.02.08 (version 4) for the above study & have had the opportunity to ask questions.
2. I understand that my participation is voluntary & that I am free to withdraw at any time, without giving reason & without this affecting my care or my family's care in any way.
3. I agree to the interview being tape-recorded.
4. I agree that any words I say may be used anonymously in the presentation or publication of the results.
5. I agree to take part in the above study.
6. I agree to my GP being notified of my participation in this study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

Appendix 11 Leaflet with sources of support

**Sexuality
&
intimacy**

There are many local and national organisations that are able to provide information and support on these important aspects of people's lives.

If you have a specific concern and would like any information about other organisations that are not listed here, please contact Bridget.

Bridget Taylor
PhD Research Student
School of Health & Social Care
Oxford Brookes University
Jack Straws Lane, Marston
Oxford OX3 0FL

Phone: 01865 482655
Email: bmtaylor@brookes.ac.uk

[Version 01 19/11/07]

**Sexuality
&
intimacy**

*Organisations
providing
information
& support*

**Bridget Taylor
PhD Research
Student**

Local services

These local services are familiar with this study and are willing to be contacted for further information or support about any of the issues raised.

Maggie's Centre

**

Tel: **

*Maggie's Centre is a drop-in information and advice service. ** is willing to provide information and support for this study's research participants who are affected by cancer. Referral to a psychologist / counsellor for further support can be made.*

MND Care Centre

**

Tel: ** (direct line)
or ** (reception)

*** provides support and information for those affected by MND. ** is willing to provide information and support for this study's research participants who are affected by MND.*

**** Hospice**

*** is a family support worker and is willing to provide support for this study's research participants who have been recruited through ** hospice.*

National Organisations

British Association for Sexual and Relationship Therapy

PO Box 13686, London SW20 9ZH

Tel: 020 8543 2707

Email: info@basrt.org.uk

Website: www.basrt.org.uk

BASRT provides information on sexual problems and lists of local therapists.

Relate

Premier House, Carolina Court

Lakeside, Doncaster DN4 5RA

Tel: 01788 573241

Email: relatedirect@relate.org.uk

Website: www.relate.org.uk

Relate centres throughout the UK offer counselling or psychosexual therapy to anyone seeking help with their relationship.

The Sexual Dysfunction Association (previously The Impotence Association)

Suite 301, Emblem House

London Bridge Hospital

27 Tooley St, London SE1 2PR

Helpline: 0870 7743571

10-4 Mon, Wed, Fri

Email: info@sda.uk.net

Website: www.sda.uk.net

The SDA provides information about male and female impotence, and its treatment.

Rape Crisis

Local Helpline: 01865 726295

6.30-9pm Mon & Thurs

6-8.30pm Sun

Website: www.rapecrisis.org.uk

Rape Crisis provides support and information for female survivors of sexual abuse or rape.

Survivors UK

Helpline: 0845 122 1201

7-10pm Mon, Tue, Thurs

Website: www.survivorsuk.org

Email: info@survivorsuk.org

Survivors is an organisation providing support for male survivors of sexual abuse and rape.

Appendix 12 Extract from response letter to university ethics committee

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Hazel Abbott, Research Ethics Lead
School of Health & Social Care
Oxford Brookes University

31st December 2007

A qualitative study to identify the meaning of sexuality & intimacy in life-limiting illness

Dear Hazel

Thank you for your letter of 18th December, suggesting a number of helpful minor amendments to my application. I have itemised my response to them in turn:

[Sections removed]

We thought that the Information Leaflet on sources of support for participants would be most helpful. However, it is unclear why Rape Crisis and Survivors UK are included. Are these organisations likely to be of relevance to the research population or does their inclusion have the potential to cause unintentional offence?

David Jones, Family Support Counsellor at Sue Ryder Care, has endorsed the inclusion of these organisations in the information leaflet. It is possible that, as a consequence of talking about their experiences of sexuality and intimacy in relation to life-limiting illness, some participants may be reminded of sexual abuse. They may not disclose this during the interview, but may find the contact details of these organisations useful.

In response to the committee's concern, I have wondered if any of the organisations listed in the leaflet might have the potential to cause offence ~ not just the two organisations that the committee has identified. I have therefore consulted some individuals from concerned communities (i.e. with life-limiting illnesses). Their response describes the leaflet as "a useful resource". Their response also indicates that the explanation I will give before *offering* the leaflet to participants is likely to prevent any unintentional offence being caused. When offering the leaflet, I shall explain that some local organisations support the study and have agreed to provide information or support to any participants who would wish to discuss any of the issues raised during the interviews. I would add that the leaflet also contains a number of national organisations that may, or may not, be useful to participants.

[Sections removed]

Yours sincerely

Bridget Taylor
PhD Research Student

Publications from this work

Taylor B, de Vocht H (2011) Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research*, 21(11), 1576-1587.

Taylor B (2011) The impact of assistive equipment on intimacy and sexual expression. *British Journal of Occupational Therapy*, 74(9), 435-442.

Marsden R, Taylor B (2012) Leaflet 20A: *Sex and relationships: for people living with MND*. Northampton: Motor Neurone Disease Association.

Marsden R, Taylor B (2012) Leaflet 20B: *Sex and relationships: for partners of people living with MND*. Northampton: Motor Neurone Disease Association.